TOWARD A NEW APPROACH TO ADDRESSING DECISION-MAKING NEEDS OF OLDER ADULTS REPRESENTING A RANGE OF COGNITIVE FUNCTION

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A dissertation submitted to the faculty of
The University of Utah
in partial fulfillment of the requirements for the degree of

Doctor of Philosophy

College of Nursing

The University of Utah

May 2015

The University of Utah Graduate School

STATEMENT OF DISSERTATION APPROVAL

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ABSTRACT

Increasingly, law, ethics, and policy recognize the right of individuals with impaired decisional abilities, including older adults with dementia, to be involved in medical treatment decisions. These shifts are in tension with current practice addressing the decision-making needs of individuals with impaired decisional abilities. In accordance with current practice, surrogates replace individuals as medical decision-makers once a health care provider or court determines that the individual lacks decision-making capacity.

The first part of this dissertation examined the history and theory of capacity determination as a component of the doctrine of informed consent to consider whether the current approach to decisional capacity is consistent with the ethical principles of autonomy and beneficence, concluding that the dichotomous structure of the current approach is inconsistent with the ethical principles because it neither offers decision-making support to individuals who may need it, nor includes individuals who remain able to meaningfully participate in their treatment decisions.

Next, using Degner's Control Preference Scale as modified by Nolan and colleagues (MCPS), a group of facility-dwelling older adults representing a range of cognitive function were asked to use the MCPS and responses to

semistructured interviews to describe their role in a past, and preferred role in a future decision-making encounter.

Evidence of validity and reliability was generated by comparing MCPS responses to the responses in a study that excluded individuals with cognitive impairment, by assessing logical and internal consistency within participants' responses, and by using triangulation to evaluate whether narrative responses and MCPS responses were aligned. All three approaches supported the validity and reliability of using the MCPS in the study population.

Overwhelmingly, participants expressed a desire to be involved in their own care, with half expressing the desire for shared decision-making with their physicians. The level of involvement desired from the family was less, with one-fourth of the participants selecting a shared role and two-thirds selecting a passive role for the family. There was a shift toward the family when participants were asked how decisions should be made if they were fully unable to participate in a future decision.

TABLE OF CONTENTS

LIST OF TABLES

LIST OF FIGURES

CHAPTER 1

INTRODUCTION

Statement of the Problem

A patient's right to accept or reject medical care is a fundamental component of contemporary healthcare, but it is widely agreed that this right is limited when a patient lacks decision-making capacity. In recent decades, however, shifts in ethics, law, and policy increasingly recognize the rights of patients with impaired cognitive capacity to participate in decisions about their treatment. These shifts are supported by evidence suggesting that older adults with impaired cognitive function who are encouraged to make choices about their lives have better outcomes across a range of measures than those who are prevented from making routine choices. The shifts are also supported by evidence suggesting that older adults with impaired cognitive function are able to state consistent preferences, goals, and values over time. The shifts are also aligned with related healthcare policy that increasingly emphasizes the need to deliver patient-centered care.

Research on decision-making capacity has been narrowly focused on how to divide adults with impaired decisional abilities into two categories: those who have and those who lack decision-making capacity as measured by criteria found

in case and statutory law (Berg, Appelbaum, & Grisso, 1996). This system of capacity assessment is emphatically dichotomous: According to practice guidelines and medical journals, a provider who concludes that a patient lacks capacity should seek informed consent from a surrogate decision-maker (Appelbaum, 2007; Reuben et al., 2014). This dichotomous view of capacity results in the exclusion of individuals from the decision-making process, even when many, perhaps even a majority, of individuals with cognitive impairment retain the ability to participate in decision-making. As a recent article declared, "The current legal-medical model for competency determinations fails to accurately reflect the complexities of declining capacity in an aging population" (Arias, 2013, pp. 134-135).

A new legal, medical, and ethical framework is needed to address the decision-making needs of older adults with impaired decisional abilities. Effective strategies are needed for eliciting decision involvement preferences from individuals with impaired decisional abilities and for meaningfully involving these individuals in decisions about medical treatment, as well as other decisions such as choice of residence. A program of research could provide direction to policy-makers, as well as patients, caregivers, providers, attorneys, and judges who need guidance to address the challenge.

Purpose of the Study

The purpose of this study is to review the ethics, policy, and law governing medical decision-making for patients with impaired cognitive function, and to describe the treatment decision-making practices and preferences of older adults

across a range of cognitive function. The data will be used to guide further research on decision-making for older adults with impaired decisional abilities.

Significance of the Study

Demographic Trends

The importance of a new decision-making approach will grow in proportion to number of older adults with cognitive impairment, which in turn will grow in proportion to the number of older adults in the population. The U.S. Census Bureau (2012) projected that the number of individuals aged 65 and older will nearly double between 2015 (47.7 million) and 2050 (92 million), while the population of individuals aged 85 and older is projected to more than triple. Often, with advancing age comes cognitive impairment. Plassman and colleagues (2007) estimated the national prevalence of dementia to be 13.93% (CI 11.42-16.44) for adults aged 71 and older. Prevalence rates increase with each decade of life, from 4.97% (CI 2.61-7.32) for age 71 to 79 years, 24.19% (CI 19.28-29.11) for age 80 to 89 years, and 37.36% (CI 25.45-49.27) for age 90 and older. Without an unforeseen breakthrough in the treatment of illness that causes impaired decisional abilities occurs, the number of older adults facing impairment in decisional abilities is likely to rise dramatically in the coming decades.

Specific Aims

Specific Aim 1 (Chapter 4)

Describe the history and theory of capacity assessment, and explore whether the current approach to capacity assessment achieves the ethical

objectives of informed consent doctrine.

Specific Aim 2 (Chapter 5)

Evaluate the validity and reliability of a modified Control Preference Scale (MCPS) (Degner, Sloan, & Venkatesh, 1997; Nolan et al., 2005) as a measure of decision-making preferences for older adults representing a range of cognitive function.

Research Question 2.1: Convergent Validity

Are participants' responses the same as or different from the responses of individuals in the study by Nolan et al. (2005), in which participants responded to a series of overlapping questions, but from which participants with moderate to severe cognitive impairment or delirium were excluded?

Research Question 2.2: Convergent Validity

Were within subject responses to related questions correlated?

Research Question 2.3: Reliability

Were participants' responses to related MCPS questions internally consistent?

Research Question 2.4: Content Validity

Did participants' responses to cognitive interviewing questions designed to elicit their understanding of interview items or spontaneous explanations of their

responses support the content validity of participants' MCPS responses?

Specific Aim 3 (Chapter 6)

Describe the decision control patterns and preferences of older adults representing a range of cognitive function.

Research Question 3.1

What level of control do older adults representing a range of cognitive function prefer in treatment decisions as weighed against the physician?

Research Question 3.2

What level of control do older adults representing a range of cognitive function prefer in treatment decisions as weighed against a companion?

Research Question 3.3

How do older adults weigh input from a physician compared to a companion during decision-making encounters: in the present with the individual's involvement, and during a hypothetical future encounter the individual unconscious and fully unable to participate in the decision-making process?

Research Question 3.4

Were there relationships between: participants' level of control (past and future preferred) weighed against the physician's level of control; participants'

level of control (past and future preferred) weighed against the decision companion's level of control; and between the relative weight given to input from the physician and companion in a future decision when the participant is involved compared to when the participant is seriously ill and unable to be involved?

Research Question 3.5

Were there relationships between level of cognitive impairment and preferred level of control?

Research Question 3.6

What characteristics of the decision-making process are important to older adults across a range of cognitive function that are not captured in the CPS?

Organization of Manuscript

This seven-chapter manuscript contains the following chapters:

Chapter 1, Introduction

Chapter 2, Background and History

Chapter 3, Methods

Chapter 4, Article: History and Theory of Capacity Assessment in a Changing Ethical, Legal, and Policy Landscape (reports the results of Specific Aim 1)

Chapter 5, Article: Validity and Reliability of Using the Control Preference Scale and Related Questions to Elicit Decision-Making Preferences of Older

Adults Across a Range of Cognitive Function (reports the results of Specific Aim 2)

Chapter 6, Listen to Me: Decision Involvement Preferences of Older Adults Across a Range of Cognitive Function (reports the results of Specific Aim 3)

Chapter 7, Discussion and Conclusions

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CHAPTER 2

BACKGROUND, LITERATURE REVIEW, AND THEORY

It is perplexing that a healthcare system that emphasizes the patient's right to make treatment decisions also embraces a system component that, with little to no oversight, categorically excludes a substantial proportion of older adults (as well as younger adults with mental health challenges and intellectual disabilities) from decisions about their care. The purpose of this chapter is to consider how the system for addressing the needs of adults with impaired decisional abilities came to be and to introduce Self-Determination Theory and the Stress Process Model, which can serve as a theoretical basis for the development of an alternative to the current approach.

Informed Consent

It is impossible to address the question of medical decision-making involvement without first addressing providers' ethical and legal obligations to obtain informed consent for treatment from a patient or a surrogate prior to providing medical treatment. The intertwining law and ethics of informed consent saw dramatic changes in the latter half of the 20th century. In the early 20th century, the law required simple consent, not informed consent to treatment.

It was articulated in the phrase, “every human being of adult years and sound mind has a right to determine what should be done with his own body” (*Schloendorff v. Society of New York Hospital*, 105 NE 92 (NY, 1914)). If a physician operated on a patient without the patient’s consent, the patient could sue the physician for battery. The nature of the information disclosed by the physician was not discussed in these cases, and the cases were uncommon (Meisel, Roth, & Lidz, 1977).

Beginning in the mid-20th century, however, judges increasingly ruled that consent was meaningless if the patient lacked necessary information about the proposed treatment (*Canterbury v. Spence*, 464 F.2d 772 (D.C. Cir. 1972); *Natanson v. Kline*, 350 P.2d 1093 (*Kan*. 1960)). No longer was a patient’s permission alone adequate to protect the physician from a claim of providing treatment without consent. After *Natanson* and *Mitchell v. Robinson*, 334 S.W.2d 11 (Mo. 1960), health care providers were required to disclose significant facts that would be necessary for the patient to intelligently consent to the proposed treatment.

Moving in parallel with the courts, ethicists in the emerging discipline of bioethics articulated and defined a patient’s right to autonomy. Drought and Koenig (2002) suggested that, because bioethics emerged in 1960s and 1970s when civil libertarians were fighting for the rights of oppressed groups of individuals, informed consent for medical treatment followed the fiercely individualistic tone of the other movements that were rooted in the right to autonomy. Whether or not it was due to the larger social and political context, the legal and ethical concept of meaningful informed consent was then, and remains

now, heavily influenced by the individualistic philosophical principal of autonomy (Faden, Beauchamp, & King, 1986). Informed consent is the primary mechanism for exercising patient autonomy in contemporary bioethics (Moreno, 1994), even when autonomy may be at odds with the practicalities of decision-making (Kapp, 1991).

Informed consent requires that the health care provider disclose to the patient sufficient information to enable the patient to understand and evaluate the need for treatment, the risks and benefits of proposed treatment, and alternatives to the proposed treatment (Berg & Appelbaum, 2001). There is much discussion about what information is sufficient, what risks and benefits should be disclosed, and the scope of alternatives that should be discussed; those discussions are outside the scope of this review. Informed consent must be voluntary, but voluntariness, like the meaning of sufficient information, is a necessary, but difficult-to-define element of informed consent that is the subject of much debate (Roberts, 2002); it will not be addressed in this manuscript. Finally, consent must be provided by a patient who has the capacity to make a health care decision (Berg & Appelbaum, 2001). Decision-making capacity holds a dominant position in the literature on autonomy's role in informed consent (Naik, Dyer, Kunik, & McCullough, 2009).

The Ethical Underpinnings of Capacity to Consent

Autonomy

The requirement that a patient have capacity to consent is framed in ethical, legal, and practical terms. Autonomy is at the heart of the informed

consent doctrine. Autonomy has been described as "nearly synonymous with human dignity" even though it is "vague at best" (May, 1994, p. 133), and its use in medical ethics is "far from clear" (Lidz & Arnold, 1992, p. 606). In the capacity assessment literature, the relationship between autonomy and capacity to consent to treatment is presented as fact, or it is used in a loose and poorly defined manner (Secker, 1999a, 1999b). What is meant by autonomy is rarely explicated or examined in the capacity assessment literature.

Kantian bioethicists promote autonomous decision-making by patients, focusing on patients' ultimate decisional authority (Secker, 1999a). Kapp (1991) describes this view of autonomy as a "pure autonomy model" (p. 620). Some scholars have been critical of the unexamined use of and references to autonomy in contemporary bioethics because the fuzziness of the concept has concrete implications for patients and providers (Beauchamp, 2004; Secker, 1999b). The dichotomous view of individuals who "lack capacity" as "nonautonomous" dominates the capacity assessment literature. If a person who lacks capacity is "nonautonomous" (Berg, Appelbaum, & Grisso, 1996, p. 380), then the person's right to have decisions made based on his or her current stated values, preferences, goals, or even moral beliefs is rendered meaningless. Alternatively, capacity can be framed as either the amount of autonomy an individual possesses or as the weight that should be given to respect for autonomy (Beauchamp, 2004). Framed in this manner, capacity is characteristic that can be measured incrementally, leaving room for respect for the autonomy of an individual with impaired decisional abilities.

The following sections from a seminal law review article by Berg, Appelbaum, and Grisso (1996), which explains the ethical and legal basis for the dichotomous view of capacity, illustrates the fuzziness of the conceptualization of autonomy the capacity framework depends on. The article remains the most thorough explication of the legal and ethical support for the current capacity assessment regime, but autonomy and its relationship to legal implications is never clearly defined. In explaining the need for capacity assessment, the authors wrote:

> Autonomy requires that the patient be offered an active role in the decision-making [sic] process. This principle recognizes that although physicians have technical expertise, patients have an essential knowledge of their own subjective values and are the best judges of their own interests. There is also an intrinsic value in autonomy; even if an outside expert is better able to make a decision, it is preferable to allow a competent individual to make his or her own choices. Embedded in the philosophical notion of autonomy are concrete requirements of capacity. To the extent that a patient's capacity is impaired with respect to abilities necessary to exercise autonomy, that person is less able to participate competently in the decision-making [sic] process. (Berg et al., 1996, pp. 346-347)

In a footnote, the authors, quoting Cutter and Shelp (1991, p. 102) explained:

> Autonomy enables a person to "examine even his naturally given needs and desires and choose whether to identify with them, shun them, or pursue them." This requires the person to form a "coherent picture of the world and of his place in it." In addition, it is "essential that the autonomous person be generally rational in his thinking and judging processes." (Berg et al., 1996, pp. 346-347)

In these two passages, the authors describe what autonomy does, why it's valuable, and what it requires, but they do not describe what it is. In another footnote, citing Cutter and Shelp (1991), the authors characterize autonomy as "refer[ring] to the capacity to make independent decisions in general" (p. 347). While they also reference "three academic models of autonomy, including total

independence, free action, and effective deliberation, and proposing a fourth model: consistency with one's values and life goals," referring to Lidz and Arnold (1992), they do not explain which of the models supports the dichotomous approach to capacity (Berg et al., 1996, p. 347).

The theory of autonomy embraced, if not clearly stated, by Berg, Appelbaum, and Grisso appears to be a formal theory, which would likely align with the effective deliberation model. A formal theory of autonomy is characterized by "formal requirements that describe the necessary characteristics or capacities of particular people or particular decision-making processes" (Schwab, 2006, p. 576). Berg and colleagues assert that "autonomy focuses on the process of decision-making [sic], not the outcome," because "an autonomous choice is one that is the product of autonomous action, regardless of whether its result is 'good' or 'bad,'" consequently, "[s]tandards should focus on the decision-making [sic] process rather than the final decision" (Berg et al., 1996, p. 352).

Schwab criticized the use of a formal view of capacity in the healthcare setting. While acknowledging the value of defining formal autonomy, "this view fall[s] short of appropriate goals of responsible healthcare" (Schwab, 2006), because the focus is on process not outcome. Schwab offered an illustration: "Autonomously desiring to have a long life would be important, and actually having a long life would not (or would be less so)" (2006, p. 577). The Berg, Appelbaum, and Grisso framework is vulnerable to this problem, because it asserts that the ability to engage in the decision-making process should be the focus of the inquiry, not whether the treatment delivered aligns with the individual's goals, values, or preferences.

Kapp (1991) offered yet another conceptualization of the relationship between autonomy and medical decision-making in the long-term care setting. Kapp's approach differs from the formal approach because it reflects the practical reality that older adults, even those viewed as having decision-making capacity, often choose to share decision-making. This practical, shared decision approach to autonomy and decision-making offers an alternative to the pure or formal conceptualizations of autonomy, and is reflected in the emerging field of supported decision-making, described below.

Gordon (2000), described the view that "independent decision-making is a myth ... every adult uses interdependent decision-making in the course of getting through the day" (p. 65). Similarly, Lidz and Arnold (1992) described "a [decision-making] model that looked at the relationship between patients' lives and their goals and commitments" (p. 607) for residents of nursing homes. Although these characterizations of the role of autonomy in decision-making may more accurately reflect the reality of decision-making, the pure autonomy/formal model described by Berg, Grisso, Appelbaum dominates the capacity-assessment literature.

Beneficence

Beneficence is "a family of overlapping virtues" including "kindness, generosity, compassion, sympathy, considerateness, sensitivity, loyalty, friendliness and affectionateness" and decency, defined as "readiness to render effective help to others in an emergency" (Ashcroft, 2007, p. 22). Beneficence and autonomy appear to be at odds in the health care setting, because

beneficence is the ethical principle that is used to justify the provision of care against the patient's will for the purpose of preserving the patient's wellbeing. For example, self-extubation is a recognized problem with mechanical ventilation, which is treated or prevented with sedation (Vassal et al., 1993). Intubation and sedation may be provided without the consent of the patient or a surrogate (Code of Ethics for Emergency Physicians, 2011) because immediate treatment is necessary to prevent death or serious harm to the patient and we presume that most patients would want these interventions.

Balancing Autonomy and Beneficence

The capacity assessment literature contains many references to the need to strike a balance between autonomy and beneficence. Appelbaum and Grisso (1988) described the process of line-drawing between those with the capacity to make decisions and those who lack that capacity as the balance between protection against bad decisions and autonomy-protection. Nearly 20 years later, Appelbaum (2007) continued to describe the process of capacity assessment as balancing autonomy against the need for protection. The emphasis on balancing between the two ethical principles suggests a need to consider autonomy only when the patient is capable of making informed decisions, with beneficence being the sole consideration when a patient has impaired decisional abilities; this balancing approach places no consideration on the goodness or badness of the decision that the patient would have made, if permitted. Rather, a balancing process that concludes that beneficence outweighs autonomy triggers the need for a substitute decision-maker: "When patients lack the competence to make a

decision about treatment, substitute decision makers must be sought" (Appelbaum, 2007, p. 1834).

Buchanan (2004), in contrast, suggests that the determination of whether autonomy should be outweighed by beneficence should be based on severity of the harm that might result from a potentially harmful decision. Decisions with little potential for harm, such as whether to consent to a blood test, would require a low level of capacity, while decisions that could result in death or serious injury would require a high level of capacity. Research suggests that this sliding scale approach is used in practice (Kim, Caine, Swan, & Appelbaum, 2006). Berg and colleagues acknowledged Buchanan's approach, but did not operationalize it in their capacity assessment approach. As dichotomous approaches to capacity, both assume that, at every point in time, for every patient, and for every decision, there is a point on a capacity spectrum at which the level of impairment renders the patient incapable of making an autonomous decision, and therefore lacking capacity. Patients' choices deserve no respect or deference and a surrogate replaces the patient as a decision maker (Appelbaum, 2007) once that point is crossed.

Cullity (2007) described an approach to balancing autonomy and beneficence that is not dichotomous. Cullity suggested that the promotion and protection of autonomy is a component of beneficence. In his view, it is wrong to view autonomy as a constraint on beneficence; rather respect for autonomy is a component of beneficence that is necessary for good medical practice. He asserted that failure to promote autonomy is often at odds with beneficence.

These conflicting accounts of how to balance autonomy and beneficence illustrate a challenge to philosophers who suggest that ethical judgments can be made by first identifying the midlevel theory, such as autonomy or beneficence, then applying the theory to specific cases to determine the ethical result (Capron & Michel, 1993). The capacity assessment literature contains a number of illustrations of this approach (Appelbaum, 2007; Moye, 2000). The midlevel approach, which is put forth as an alternative to deducing ethical rules from fundamental moral theories, such as Kantian deontology or Utilitarianism, was appealing in bioethics because the use of fundamental moral theory to resolve the types of ethical dilemmas that arise in bioethics had not been effective. Unfortunately, midlevel theories were no more successful at resolving ethical dilemmas than fundamental theories because they lack the ability to prioritize one theory over another (Capron & Michel, 1993).

The Elements of Decision-Making Capacity

As the doctrine of informed consent was developing, there was a very little agreement on how to define the capacity to consent to treatment in law or medicine (Roth, Meisel, & Lidz, 1977). In a series of articles that attempted to bring structure to the field, Roth and his colleagues identified five possible elements of capacity: evidencing a choice, 'reasonable' outcome of choice, choice based on 'rational' reasons, ability to understand, and actual understanding (Roth, Meisel, & Lidz, 1977).

The MacArthur Treatment Competence Study, the single most influential research effort on capacity assessment to date, began in 1988 and was led by

Appelbaum and Grisso. The effort developed and expanded on the concepts first introduced by Roth, Meisel, and Lidz. The study was designed to generate empirical data that could inform policy makers and clinicians about capacity among people hospitalized with mental illness (Appelbaum, 2004; Appelbaum & Grisso, 2004). As Appelbaum wrote, "a compound standard of competence, drawn from the case law and often reflected in statutes and commentary, formed the basis for the MacArthur Treatment Competence Study" (1998, p. 379).

Berg, Appelbaum, and Grisso articulated a "legal standards" approach to capacity with four elements (Berg et al., 1996). ***Communicating*** a choice is largely self-explanatory, but, in addition to either expressing or failing to express a choice, it includes the ability to communicate a consistent choice over time. A patient must be able to ***understand*** information about the benefits and burdens of the proposed treatment, as well as alternative treatments. Grisso and Appelbaum (1998) emphasized the need for a provider to assure that adequate information is given to the patient to support understanding, so that a patient's capacity is not called into question because the provider has failed to disclose sufficient information to the patient. ***Appreciation*** is the ability to assess the proposed treatment as it relates to the person making the decision, not just as an abstract concept. Finally, ***reasoning*** involves the ability to evaluate, weigh, and manipulate the information received. The assessment of reasoning does not consider the reasonableness of the outcome, but focuses instead on the consistency of the reasoning (Appelbaum & Grisso, 1988, p. 1636). Berg, Appelbaum, and Grisso (1996) asserted that a patient whose capacity is in question should be required to demonstrate the ability to meet all four of the

legal standards, although they acknowledged that statutory and case law often required only a subset of the four.

In addition to establishing the legal standards capacity construct, the effort developed and tested a number of preliminary instruments for measuring decision-making capacity, such as the *Thinking Rationally About Treatment* measure, which evaluated the patient's reasoning about information when making a treatment decision (Grisso & Appelbaum, 1993). Preliminary instruments were combined into the MacArthur Capacity Assessment Tool – Treatment (MacCAT-T) (Grisso & Appelbaum, 1995) and the MacArthur Capacity Assessment Tool – Research (MacCAT-R) (Grisso, Appelbaum, Mulvey, & Fletcher, 1995). If these or similar instruments designed to assess decision-making capacity suggest that a patient's capacity may be impaired, measures should be taken to assure that the impairment is not treatable or reversible (Appelbaum, 2007), and to assure that sensory disabilities are addressed (Sugarman, McCrory, & Hubal, 1998). If, however, additional measures fail to improve the patient's abilities, Appelbaum and others recommended that providers identify a surrogate decision maker who will make decisions on behalf of the impaired patient (Appelbaum, 2007). No mention is made about the role of the individual from this point forward.

A number of concerns about the legal standards approach for defining capacity were expressed in 1996, shortly after the publication of the MacCAT-R. While authors published in a 1996 special issue of *Psychology, Public Policy, and Law* broadly agreed that the MacArthur Treatment Capacity Study had made significant contributions to the field of capacity assessment, they expressed a

range of concerns about the instruments and constructs. Kapp and Mossman (1996), for example, cautioned against the use of a "capacimeter" for evaluating decision-making capacity. They acknowledged the appeal of an instrument that could objectively navigate the tension between extending autonomy to those who have the ability to make decisions and imposing protective measures on those who are unable to make decisions (Kapp & Mossman, 1996). Despite the concerns raised by Kapp and Mossman, as well as others (Kirk & Bersoff, 1996; Slobogin, 1996; Stefan, 1996; Weyrauch, 1999) the capacity construct defined by Appelbaum and Grisso under the umbrella of the MacArthur Treatment Capacity Study has become ubiquitous.

The capacity assessment research published by Appelbaum, Grisso, and a variety of colleagues (Appelbaum, 2007; Appelbaum & Grisso, 1988; Appelbaum & Grisso 1995; Appelbaum, Lidz, & Meisel, 1987 ; Berg et al., 1996; Berg & Appelbaum, 2001; Grisso & Appelbaum, 1995a, 1995b, 1995c, 1996, 1998a, 1998b; Grisso, Appelbaum, Mulvey, & Fletcher, 1995), Marson and a variety of colleagues (Dymek, Atchison, Harrell, & Marson, 2001; Earnst , Marson, & Harrell, 2000; Marson, Dymek, & Geyer , 2001; Marson & Harrell, 1999; Marson, Annis, McInturff, Bartolucci, & Harrell, 1999; Marson, Chatterjee, Ingram, & Harrell, 1996; Marson, Cody, Ingram, & Harrell, 1995; Marson, Earnst, Jamil, Bartolucci, & Harrell, 2000; Marson, Hawkins, McInturff, & Harrell, 1997; Marson, Ingram, Cody, & Harrell, 1995; Marson, McInturff, Hawkins, Bartolucci, & Harrell, 1997; Marson & Moye, 2007; Marson, Schmitt, Ingram, & Harrell, 1994; Moye, Butz , Marson, & Wood, 2007; Moye & Marson, 2007), Karlawish and a variety of colleagues (Karlawish, 2008, Karlawish, Casarett, James, Xie, &

Kim, 2005, Kim , Karlawish, & Caine, 2002), Moye and a variety of colleagues (Moye, 1996, 1999, 2000, 2007; Moye, Armesto, & Karel, 2005; Moye, Gurrera, Karel, Edelstein, & O'Connell, 2006; Moye, Karel, Azar, & Gurrera, 2004; Moye et al., 2008; Moye & Marson, 2007), Karel and a variety of colleagues (Karel, Gurrera, Hicken, & Moye, 2010), and others have built a body of literature addressing a variety of measures and correlates of capacity. The few publications among these that address what happens after a finding of incapacity have directed providers faced with an incapacitated patient to seek a surrogate decision maker to make decisions on behalf of the incapacitated patient (Appelbaum, 2007; Reuben et al., 2014). The ethical justification for this recommendation is two-fold and involves interplay between beneficence and autonomy: When individuals lack decision-making capacity, the interest in protecting those individuals is primary, while the interest in promoting autonomy recedes (Appelbaum, Appelbaum, & Grisso, 1998). This justification is consistent with the view that individuals who lack capacity are nonautonomous.

A somewhat different way to frame the shift to a surrogate is based on the concept of precedent autonomy: An individual who appoints an agent through a special power of attorney for health care or similar document allows the surrogate to exercise autonomy on his or her behalf in the event of a future loss of capacity (Francis, 2000). For this framework to effectively protect an individual's autonomy, however, it is necessary for surrogates to promote the individual's preferences. As discussed below, the research on surrogate decision-making casts doubt on surrogates' abilities to serve in this role.

Assumptions in the Legal Standards Approach

Surrogate Decision-Making

A persistent assumption evident in the capacity assessment literature is that the best way to promote the interests of individuals with impaired decisional abilities is to replace them with surrogate decision-makers. Since the publication of the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research report, *Making Health Care Decisions* (1982), substituted judgment has been the gold standard for surrogate decision-making. The substituted judgment standard requires a surrogate to make the decision that the patient would have made if the patient had the capacity to make the decision, considering the values and preferences of the patient that are known by the surrogate (Coverdale, McCullough, Molinari, & Workman, 2006). Substituted judgment is viewed as more protective of patient autonomy than the best interest standard, in which the surrogate chooses the option that the surrogate views as being in the patient's best interest (Francis, 2000).

Unfortunately, research on surrogate decision-making casts doubt on the validity of the assumption that surrogates are able to effectively apply this standard. A meta analysis by Shalowitz, Garrett-Mayer, and Wendler (2006), which evaluated 16 studies, 151 hypothetical scenarios, 2,595 surrogate-patient pairs, and 19,526 paired patient surrogate responses, revealed that in a third of all decisions, the surrogate was unable to accurately predict what the patient wanted. Similarly discouraging were the results of a randomized controlled trial that considered the effect of advance directives on a surrogate's ability to predict an older adult's preferences for care (Ditto & Danks, 2001). In the study,

outpatients (N = 401) aged 65 and older were randomly assigned to one of five groups. Four interventions were evaluated: advance health care directives with discussion, advance health care directives without discussion, valued life activities directives with discussion, and valued life activities directives without discussion. In the control group, 72% of the surrogates accurately predicted the patient's preferences in nine different scenarios. Surrogates were unable to make decisions in accordance with the substituted judgment standard at higher rates, even with the support of interventions designed to improve participant performance; none of the interventions improved surrogates' performance. The authors concluded that the study demonstrated the ineffectiveness of interventions to improve the quality of substituted judgment (Ditto & Danks, 2001). A 2013 study by Gao et al. (2013) found low levels of agreement between the end-of-life care approaches preferred by patients and by caregivers making decisions on behalf of patients (Φ = 0.10; $\chi 2$ = 2.32, df = 1, p = 0.13).

In a study evaluating quality of life judgments, Feinberg and Whitlatch (2001) found that surrogate decision-makers' views of a patient's quality of life were related, but not identical, to the patient's. Covinsky et al. (2000) found that surrogates were able to predict patient's preferences only 37% of the time; surrogates predicted that patients would "rather die" than live in a nursing facility in 14% of the cases where a patient was "very willing" to live in a nursing facility. Still other studies that have shown that older adults' treatment preferences vary over time (Ditto et al., 2003; Fried, O'Leary, Van Ness, & Fraenkel, 2007). Shalowitz et al. (2006), called for researchers to investigate new

ways to make decisions for patients with diminished capacity that are more likely to reflect patient preferences.

A recent study raises concerns about the ability of caregivers to articulate the values of older adults with dementing illness. Reamy, Kim, Zarit, and Whitlatch (2013) found that caregivers became less able to effectively represent the interests of older adults in decision-making over time because they de-emphasized the importance of the older adult's values and preferences. The caregiver's quality of life predicted their ratings of the importance of the older adult's values and preferences.

An implicit assumption of the legal standards approach to capacity is that a surrogate decision-maker is better than an impaired patient as representing the autonomous preferences of the patient. These studies cast doubt on that assumption. In turn, the studies reinforce the need to develop a new model of decision-making for adults with impaired decisional abilities.

Abilities of Older Adults with Dementia

There is evidence that individuals with impaired decisional abilities can be reliable informants, can consistently report preferences, goals, and values, and often wish to be involved in the decision-making process. Involvement in decision-making can improve a variety of outcomes.

In a study of 99 individuals with dementia Brod, Stewart, Sands, and Walton (1999) found that 95 participants were able to respond to a quality-of-life questionnaire; 50 of those who were capable of completing the questionnaire had a Mini Mental Status Examination (MMSE) score between 13 and 18. Logsdon

and colleagues have published a number of studies in which they have demonstrated that many individuals with dementia can respond to a quality-of-life questionnaire (Logsdon, Gibbons, McCurry, & Teri, 1999; R. G. Logsdon, Gibbons, McCurry, & Teri, 2002). Mak (2011) found that individuals with dementia provided reliable information on goal pursuit and purpose in life. Whitlatch, Piiparinen, and Feinberg (2009) concluded that individuals with dementia were able to report preferences regarding autonomy, burden, social relations, and safety/quality of care. In addition, persons with dementia can consistently report demographics, facts, general preferences, involvement in daily living, preferences for care, and state-dependent preferences (Clark, Tucke, & Whitlatch, 2008; Feinberg & Whitlatch, 2001, 2002; Menne, Tucke, Whitlatch, & Feinberg, 2008; Whitlatch, Feinberg, & Tucke, 2005). Karel, Moye, Bank, and Azar (2007), found that individuals with dementia were able to articulate values and to respond to a values questionnaire, and responses of individuals with dementia were as stable when evaluated 9 months later as the responses of individuals who did not have a dementia diagnosis. When combined, these studies provide support for the view that individuals with dementia can provide reliable, consistent reports on states and preferences that are relevant to the treatment decision-making process.

Benefits of Decision-Making Involvement

Empirical evidence suggests that greater involvement in decision-making is correlated with better health-related outcomes than are found among individuals with less involvement, for patients both with and without cognitive

impairment. In breast cancer treatment, for example, patient participation in decision-making is associated with higher satisfaction with care, better provider compliance with quality measures, and improved patient quality of life (Maly, Umezawa, Leake, & Silliman, 2004). Menne, Judge, and Whitlatch (2009) found that individuals with dementia who rated their decision-making involvement as high also reported higher quality of life. Kasser and Ryan (1999) identified an association between reports of greater autonomy and improved psychological outcomes, as well as decreased mortality, among nursing home residents. Dawson, Powers, Krestar, Yarry, and Judge (2013) showed that, among individuals with dementia, higher reported self-efficacy was correlated with higher self-rated quality of life.

In view of a growing body of evidence that supports patient involvement in care decisions, the Institute of Medicine in 2001 advocated patient-centered care (Institute of Medicine Committee on Quality of Health Care in America, 2001). The VA has adopted the Chronic Care model, which is based on the premise that "good quality chronic care is characterized by productive interactions between informed and activated patients and a prepared, proactive health care team" (Rodriguez, Appelt, Switzer, Sonel, & Arnold, 2008, p. 441). The patient-centered care that is central to the VA's Chronic Care Model will demand new strategies for including individuals with impaired decisional abilities in decisions about their care.

Preferences for Decision-Making Involvement

In a study considering the decision-making preferences of individuals with dementia, Hirschman and colleagues asked 48 individuals with Alzheimer's disease if they would want to participate in decisions about their care, and 91.7% reported that they did; 70% of their paired caregivers thought the person with Alzheimer's disease would want to participate (Hirschman, Joyce, James, Xie, & Karlawish, 2005). The study provided insight into the caregiver/person with Alzheimer's disease dyad that begins to explain how variables such as caregiver gender and relationship between the dyad members could influence involvement in decisions. Hirschman and colleagues concluded the article by emphasizing the importance of exploring further "how patient-caregiver dyads actually make … decisions and [how to] improve the process of decision-making" (Hirschman et al., 2005, p. 387). Citing Hirschman's study, the American College of Physicians, along with 10 other medical associations, have endorsed ethical guidelines that encourage providers to make clinical encounters "patient-centered, allowing for maximum appropriate patient autonomy and participation in decision-making" and to support "patients' ongoing participation about their care" (Mitnick, Leffler, & Hood, 2010, p. 256).

Supported Decision-Making

As with many emerging paradigms, supported decision-making means different things to different people in different settings. This work adopts the description used by Kohn, Blumenthal, and Campbell (2013): Supported decision-making is a process wherein an adult with impaired decisional abilities

is the ultimate decision-maker, receiving support from one or more individuals or entities who assist in making and communicating decisions. Supported decision-making necessarily includes the individual in the decision-making process, in contrast to substituted judgment, which assumes that the person is unable to be included in the decision-making process. Some supported decision-making models involve court proceedings, while others remain informal or lack legal enforceability (Gordon, 2000; Kohn et al., 2013; Pathare & Shields, 2012). Models are being institutionalized in legislation, such as those in Sweden, British Columbia, and Saskatchewan (Surtees, 2010).

In the U.S., supported decision-making has received little attention in court-ordered decision-making structures such as guardianships, where substituted judgment dominates, and where an adult would typically lose the legal right to make decisions when a court determines that the person needs legal protection. This contrasts with legally recognized supported decision-making models that emerged in European countries such as Norway in the 1990s, where a court could put a decision-making assistant in place without depriving the individual in need of protection of the legal right to make decisions (Blankman, 1998). More recently, supported decision-making has been recognized in legal structures in the Canadian provinces of British Columbia and Saskatchewan (Pathare & Shields, 2012; Surtees, 2010). The international trend turned away from exclusion and toward legal structures designed to preserve adults' rights to make decisions with support when the United Nations passed the game-changing Convention on the Rights of Persons with Disabilities (CRPD) (United Nations, 2006)

Article 12, paragraph 2 of the CRPD states, “Parties shall recognize that persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life” (United Nations, 2006). The Optimal Protocol for implementing the CRPD encourages supported decision-making processes that view the individual as the decision-maker, with others in roles such as providing explanations to the individual and interpreting the individual’s preferences. One hundred fifty-eight countries (including the U.S.) have signed, and 143 countries (excluding the U.S.) have ratified the CRPD. As one scholar observed, “Article 12 marks an important paradigm shift from the practice of depriving people of their rights simply on the basis of their perceived lack of capacity to the promotion of national policies and laws which comport to the goals and principles of the CRPD, including autonomy, dignity, and independence” (Kanter, 2008, p. 560).

While U.S. laws are trending toward increased protection of the rights of adults to make their own legal decisions, no state’s guardianship laws are designed to put a supported decision-maker in place without removing the adult’s legal right to make medical decisions. A consensus statement developed during the Third National Guardianship Summit implicitly endorsed shared decision-making within the context of guardianship when it stated that guardians have the obligation to “help the person express his or her goals,” Symposium, *Third National Guardianship Summit Standards and Recommendations*, 2012 Utah Law Review 1191 (2012). Regulations from the U.S. Centers for Medicare and Medicaid Services (CMS) characterized “person-centered planning” as a supported decision-making process that could be used for adults with impaired decisional abilities both inside and outside of a legal guardianship structure.

According to CMS, an individual with impaired decisional abilities "directs the [decision-making] process, with assistance as needed or desired from a representative of the individual's choosing" 42 C.F.R. 440.167 (2011). This decision-making approach "is intended to identify the strengths, capacities, preferences, needs, and desired measurable outcomes of the individual." The decision-making companion should be "freely chosen by the individual" 42 C.F.R. 440.167 (2011).

The increasing emphasis on person-directed healthcare and the rights of adults with disabilities dovetail with emerging emphasis on supported decision-making, even in the absence of the legal structures that support the concept in Canada and other countries. Although Kohn and colleagues (2013) describe the evidence for supported decision-making as "meager" (p. 1135), the concept is supported both in theory, as discussed in the next section, and by the empirical evidence of the harms caused when individuals are excluded from decisions and the benefits of inclusions, discussed above.

Theory

Two theories are relevant to considering models for addressing the decision-making needs of older adults with impaired decisional abilities, but none is entirely adequate for the purpose of supporting model development. Theories that are relevant to treatment decision-making for individuals with impaired cognitive capacity are described below.

Stress Process Model

Menne and colleagues have used a modified stress process model to explain decision-making involvement among older adults with dementia (Menne et al., 2009; Menne & Whitlatch, 2007). The stress process model addresses the role of relationships between care receivers and caregivers, the role of social factors that influence stress in chronic illness, and the role of moderators in making the stress of chronic illness better or worse (Judge, Menne, & Whitlatch, 2010). The stress process model was used in these studies to identify factors that can predict quality of life so that interventions to improve quality of life might be targeted at those factors (Menne et al., 2009). Decision-making involvement has been shown to predict quality of life in the studies, but the stress process model does not provide guidance on the ethical and practical issues that must be addressed in developing a model of decision-making inclusion.

Self-Determination Theory

Self-determination theory supports the need for a model of decision-making inclusion. Deci and Ryan's self-determination theory suggests that autonomy, perception of competence, and relatedness are essential psychological needs that environment and interpersonal relationships can either foster or frustrate (Deci & Ryan, 1985; Ryan & Deci, 2001). If these needs are not met, self-determination theory predicts that poor health, conflict, and distress result (Kasser & Ryan, 1999). Like the stress process model, self-determination theory supports the development of an inclusive decision-making model, but it does not help to resolve the ethical and practical issues in developing the model. Self-

determination theory supports the move toward person-centered treatment decision-making, which in turn, supports the use of supported decision-making.

Development of a Novel Model for Inclusive Decision-Making

Self-determination theory and the stress process model are relevant to questions about decision-making. They do not, however, answer questions about the balance between self-direction and protection, the legal and practical demands of the informed consent process, and the role of other individuals (e.g., family members or friends) in the decision-making process. Addressing these questions will require a more thorough understanding of health care decision-making from the perspective of the individual, other involved nonprofessionals, and the health care provider. This study will help to provide that understanding.

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CHAPTER 3

RESEARCH DESIGN AND METHODS

The purpose of this chapter is to describe the methods used in this study. Under Aim 1, an analysis was conducted to determine whether the current approach to capacity assessment is consistent with ethical objectives of informed consent. To achieve this aim, an historical review of capacity assessment was conducted, focusing on the mid-1940s through the present. The current system was then evaluated in light of emerging empirical evidence about the benefits of including people in decisions about their lives, and shifting views of how to ethically address the needs of people with disabilities. Finally, future directions in capacity assessment and decision-making for people with impaired decisional abilities were discussed.

The study was conducted to evaluate the validity and reliability of the Modified Control Preference Scale (MCPS) as a measure of decision-making preferences for older adults representing a range of cognitive function (Aim 2). Studies characterizing older adults' decision-involvement preferences have typically excluded individuals with impaired cognitive function, as measured by cognitive screening instruments or diagnosis (Nolan et al., 2005). Studies evaluating the experiences of individuals with dementia typically use proxy

reports from caregivers (Beard & Neary, 2013), not the views of the individuals, because people with dementia are "deemed incapable … of even narrating their own experience of illness" (p. 131).

This study used validated instruments to elicit decision-making preferences of older adults across a range of cognitive function, including individuals who would likely be judged to lack decisional capacity under the legal standards approach described in Chapter 2. In addition, semistructured interview questions guided by cognitive interviewing techniques were asked to elicit narrative descriptions of participants' preferences. Quantitative and qualitative data were analyzed to determine whether the use of the MCPS was valid and reliable in the study population.

Participants' decision-making preferences were described (Aim 3) using their responses to the MCPS and their responses to semistructured interview questions. A finding that participants' preferences for involvement are incompatible with a decision-making model that categorically excludes individuals with impaired decisional abilities from decisions about their care would support the need for further research to serve as the foundation for a new model that involves individuals with impaired decisional abilities in decisions about their care.

Older adults with impaired decisional abilities have been excluded from studies about decision-making preferences in the past. An understanding of the preferences of individuals whose role in treatment decision-making may be limited by the legal standards approach to defining decision-making capacity can help guide the development of a model of inclusive decision-making.

Specific Aim 1: Methods

Describe the history and theory of capacity assessment, and explore whether the current approach to capacity assessment achieves the ethical objectives of informed consent doctrine.

To understand the origins of the current model of treatment decision-making capacity, the first step was to trace the history and theory of decisional capacity and the emerging field of capacity assessment. First, the seminal article on the subject, *Constructing Competence: Formulating Standards of Legal Competence to Make Medical Decisions,* by Berg, Appelbaum, and Grisso (1996), was reviewed, as well as cases, statutes, research studies, and ethics texts that were cited in the article. The purpose of the review and analysis was to describe how the authors used case and statutory law, as well as ethical principles, to identify the four elements of the legal standards approach to defining and assessing capacity.

Two articles by Meisel, Roth, and Lidz, *Toward a Model of the Legal Doctrine of Informed Consent* (1977) and *Tests of Competency to Consent to Treatment* (1977), were predecessors to the article by Berg et al. (1996). Again, cases, law review articles, and ethics texts cited in these articles were reviewed and analyzed. The focus of the analysis remained on the use of case and statutory law to strike a balance between autonomy and beneficence. Additional research included the review of original sources cited by Roth, Meisel and Lidz, as well as Berg, Appelbaum, and Grisso.

A primary focus of the analysis was the ethical principles of autonomy and beneficence. In addition to traditional considerations, such as Kantian notions of

autonomy, more recent conceptualizations were considered, such as Secker's view that beneficence requires the promotion of autonomy (Secker, 1999a, 1999b). The role of capacity in informed consent doctrine was also considered.

After describing the legal and ethical framework of capacity, assumptions that are implicit, and occasionally explicit, in the legal standards approach to characterizing capacity were identified and discussed. For example, the assumption that a surrogate applying a substituted judgment standard can best address the decision-making needs of an individual with impaired decisional abilities was explored. Research studies addressing the abilities of people with dementia and the benefits of decision involvement were then considered in evaluating the assumptions. Finally, the sparse literature on supported decision-making was explored to consider whether supported decision-making could serve as an effective alternative to the current dichotomous approach to capacity assessment.

Specific Aims 2 and 3

Rationale

The measurement of decision-making capacity using the legal standards paradigm has been extensively studied (Moye, Marson, & Edelstein, 2013). Studies have focused on the relationships between various measures of cognitive function and measures of capacity. The next step – replacing the "incapacitated" patient with a surrogate decision-maker – has received little attention. There is a dearth of research on (1) whether older adults with impaired decisional abilities would want to be involved in making treatment decisions, (2) if they did want to

be involved, how they would want to be involved in the decisions, and (3) how they would perceive exclusion from the decision-making process. If individuals with impaired decisional abilities want to be involved in treatment decisions, and if supporting their involvement were beneficial to their wellbeing and therefore supported by the ethical principle of beneficence, further research, along with changes in law, policy, and clinical guidelines should be considered.

Most studies assessing decision involvement preferences exclude older adults with dementia or those with a score on the Short Portable Mental Status Questionnaire (SPMSQ) (Pfeiffer, 1975), Mini Mental State Examination (MMSE) (Folstein, & McHugh, 1975), or Montreal Cognitive Assessment (MoCA) (Nasreddine et al., 2005) below a set cut point. This portion of the study evaluated whether instruments validated for use in other populations of adults would effectively, reliably, and validly captured the decision-involvement preferences of older adults across a range of cognitive function.

Design

Employing a mixed methods design, this study used a modified Control Preference Scale (MCPS) (Degner et al., 1997; Nolan et al., 2005) and semistructured interviews guided by cognitive interviewing techniques to elicit participants' preferences. Mixed methods are used to study the phenomenon because "different aspects of reality lend themselves to different methods of inquiry" (Sandelowski, 2000a, p. 247). Health care decision-making is a very complex interaction between patient and provider, and in the geriatric population, the complexity is compounded further by the presence of one or more

individuals such as an appointed health care agent, family member, or friend (Kapp, 1991). This complicated interaction will be most effectively described and clarified by combining research methods, as described below.

Sample

A convenience sample of participants residing in two assisted living facilities and three nursing homes were recruited. Attempts to recruit participants in a hospital setting and a geriatrics out-patient clinic, and through a newsletter on Alzheimer's Disease research were unsuccessful. Facilities were selected because they were expected to have a substantial number of eligible participants, but differences were expected between individuals living in different types of settings.

The sample was larger than a typical qualitative study, where researchers recruit participants until saturation is reached and no new themes emerge. At the same time, the sample was small for a quantitative study, where a smaller sample has less power to detect significant differences among participants. A sample size exceeding 35 was thought to be sufficient for a preliminary descriptive study including a statistical evaluation of relationships between individuals and groups and within subjects. In retrospect, the sample appears to have been adequate because major themes repeated, with no new themes emerging, prior to the final interview. As discussed below, significant relationships and differences were found among a number of variables.

Individuals were considered for participation if, according to their health record and/or the judgment of facility personnel and/or the investigator, they

were age 65 or older and English-speaking, had sensory, physical, and cognitive function sufficient to participate in the interview, and were currently free from active mental illness or chemical dependency.

A contact person at each site reviewed a list of residents and identified residents who were viewed as meeting inclusion criteria. A total of 62 individuals were invited to participate. Nineteen declined to participate for a 31% refusal rate. Among those who began the consent process, three were judged by the researcher to lack sufficient understanding of the nature of the study to provide informed consent to participate, discussed further below, and two with acute illnesses were unable to stay awake through the consent process. Thirty-eight participants were enrolled in the study, but one withdrew before completing the demographic questionnaire due to a scheduling conflict. See Figure 3.1.

Reasons for declining to participate included fatigue, pain, and scheduling conflicts, but the majority of individuals who did not participate did not provide a reason.

Throughout the consent process and interviews, participants were offered the opportunity to stop the interview if signs of physical or emotional distress were observed. Two individuals declined to complete the MoCA due to pain and fatigue.

The sample was influenced by the judgment of the facility staff, consequently there was a risk referrals would exclude individuals who the contact person viewed as lacking the ability to participate, but who could have participated. All of the facilities either referred people who were found to be unable to participate, or whose cognitive abilities were substantially impaired;

the interviewer did not see evidence that facilities screened out eligible participants. In addition, there was a risk that the contact person might not have referred individuals viewed as being critical of the facility. Participants at all but one facility expressed frustration or criticism about the facility or policies, and one or more participants at three of five facilities were very critical. Again, there was no evidence that individuals were not referred because they had criticisms of the facilities.

Even if referrals were not deliberately biased, there were likely biases in the study population. An interview estimated to take about 1 hour is both physically and cognitively demanding, and would have excluded individuals who viewed themselves as unable to meet that demand. The study involved only individuals residing in facilities, not individuals living in their homes without support, which affected some findings.

The study protocol provided for oversampling individuals with impaired cognitive function if more than 15 of the participants recruited had no known cognitive impairment. As noted in the results section, 34 of 37 participants had a positive screening test for cognitive impairment, so oversampling was unnecessary.

Human Subjects Protection and Informed Consent

The study was approved by the University of Utah Institutional Review Board. In accordance with the study protocols, consent was obtained by the investigator, an elder law attorney with training and experience in medical ethics, consenting participants for research studies, and evaluating the capacity of adults

with cognitive impairment according to a range of legal standards. In addition to reading the IRB-approved consent form to participants, the investigator asked participants to explain, in their own words, the risks and benefits of participation, and describe what study participation would require of them. The investigator considered whether potential participants had the requisite ability to communicate, and to rationally evaluate, understand, and appreciate the nature of the study, their role in the study, and the risks and benefits of participating in the study (Grisso, Appelbaum, Mulvey, & Fletcher, 1995). For example, a potential participant who was approached was not enrolled when she expressed the desire to help, but was unable to demonstrate an understanding of how her participation would contribute to the study, even after different explanations were provided. Throughout the consent process and interviews, participants were offered the opportunity to stop the interview if signs of physical or emotional distress were observed.

Setting

Interviews were conducted in quiet locations selected by the participant, such as conference rooms or the participant's room. In some instances, interviews were conducted in quiet public areas, such as the dining room between meal times, or other areas selected by the participant.

Measures

The following instruments were used in the study:

- Modified Control Preference Scale (MCPS)

- Satisfaction with Decision Scale (SDS)
- Montreal Cognitive Assessment (MoCA)

These instruments, procedures for use, and analysis are described in detail in Chapters 6 and 7. In addition, the Medicare Current Beneficiary Survey, Usual Source of Care Questionnaire (2010) was used to generate a description of the role of a decision companion. The question series helped provide structure to the portion of the interview designed to elicit information about the role of a companion, but the data were not analyzed or reported because many questions were irrelevant to individuals living in residential settings.

Procedures

After they provided demographic information, participants were asked to identify a person or persons involved in making decisions about their healthcare, and for participants who had a person involved, the Medicare Current Beneficiary Usual Source of Care questions were asked, to the degree they were relevant. Participants were then asked to identify an instance where they were involved in a treatment decision (the "target decision") and to provide details about the decision that was made and how it was carried out. The SDS was then administered, with the participant asked to focus on the target encounter when asking the questions. After two individuals who were unable identify a target encounter were not asked the SDS, the remainder of participants who could not describe a target encounter were asked to respond to the SDS questions as they applied to a typical doctor's appointment.

Participants with sight were provided with a visual representation of the MCPS items for eliciting their relationship with the physician, as shown in Figure 3.2. Probing questions were asked, for example, if the participant said, "I make the decisions" without clearly indicating one of the options, they were directed to the visual representation and asked, "Did you seriously consider your doctor's opinions before making the decisions, or do you make decisions on your own?" If the participant's choice between options was ambiguous, questioning would proceed in this manner.

Participants were then asked to set aside the target encounter and instead describe the perfect decision-making encounter. If a participant appeared to be fatigued or frustrated or irritated at the question series, and if the prior responses suggested that the answer would be the same as it was for the first question series, the question was framed as a comparison with the past encounter. For example, a participant was asked, "Would the perfect decision-making process be the same as the process you described for the decision to operate on your knee?" If the response was anything other than unconditional affirmation, then the question series was repeated. The same series was repeated, but with a focus on the decision companion. At the conclusion of both question series, participants were asked if the CPS accurately captured their view of the decision-making process, and were asked to describe what was not captured.

Participants were then asked what the doctor should consider in forming opinions about treatment. If they were unsure, prompts would be given such as the following: "Are there things about you, about how you live your life, that the doctor should consider?" and "Some people think it is important that the doctor

think about their religious or spiritual values, the cost of treatment, or whether treatment might affect their ability to live where they live now. Would you want your doctor to consider any of these?" Participants were then asked to report how they weigh input from the physician and companion. At the end of the interview, all participants were asked if there was anything else about their decision-making process that they wanted to share.

To understand how the participants want to engage with the physician in making decisions, participants were asked at the end of the interview in semistructured questions if they would want a physician to disclose information about a foreseeable characteristic of a newly diagnosed serious illness or side effects of a treatment for a new or existing illness. Types of information included physical side effects such as nausea or pain, functional impairment, such as inability to walk, and cognitive impairment such as the inability to recognize people or confusion, and life expectancy. Like the Medicare Current Beneficiary Survey, the questions generated narrative descriptions of participant experiences and preferences, but specific responses were not reported.

Participants were invited to provide the name and contact information of the decision companion in order to obtain the companion's understanding of the participant's preferences. This portion of the study was discontinued when none of the first 10 companions responded to voicemail messages or emails inviting their participation.

The MoCA was administered at the end of the interview.

Participants each received $10 as a token of appreciation for their participation.

Data Organization and Analysis

Data organization and analysis relevant to Aim 2 are described in detail in Chapter 5, and data organization and analysis relevant to Aim 3 are described in detail in Chapter 6.

Study Limitations

This study has a number of limitations. The sample size was small, so generalizability is limited. The small sample size also limited the ability to observe significant relationships among variables. Participants all lived in residential settings in a Mountain West state; individuals in community settings may view the issues explored differently from those in residential settings. Participants were overwhelmingly White, and were, on average, highly educated; there may have been selection bias due to referrals and self-selection. It is possible that individuals who declined to participate viewed their roles in the decision-making process differently from those who enrolled in the study due to frailty or level of cognitive impairment.

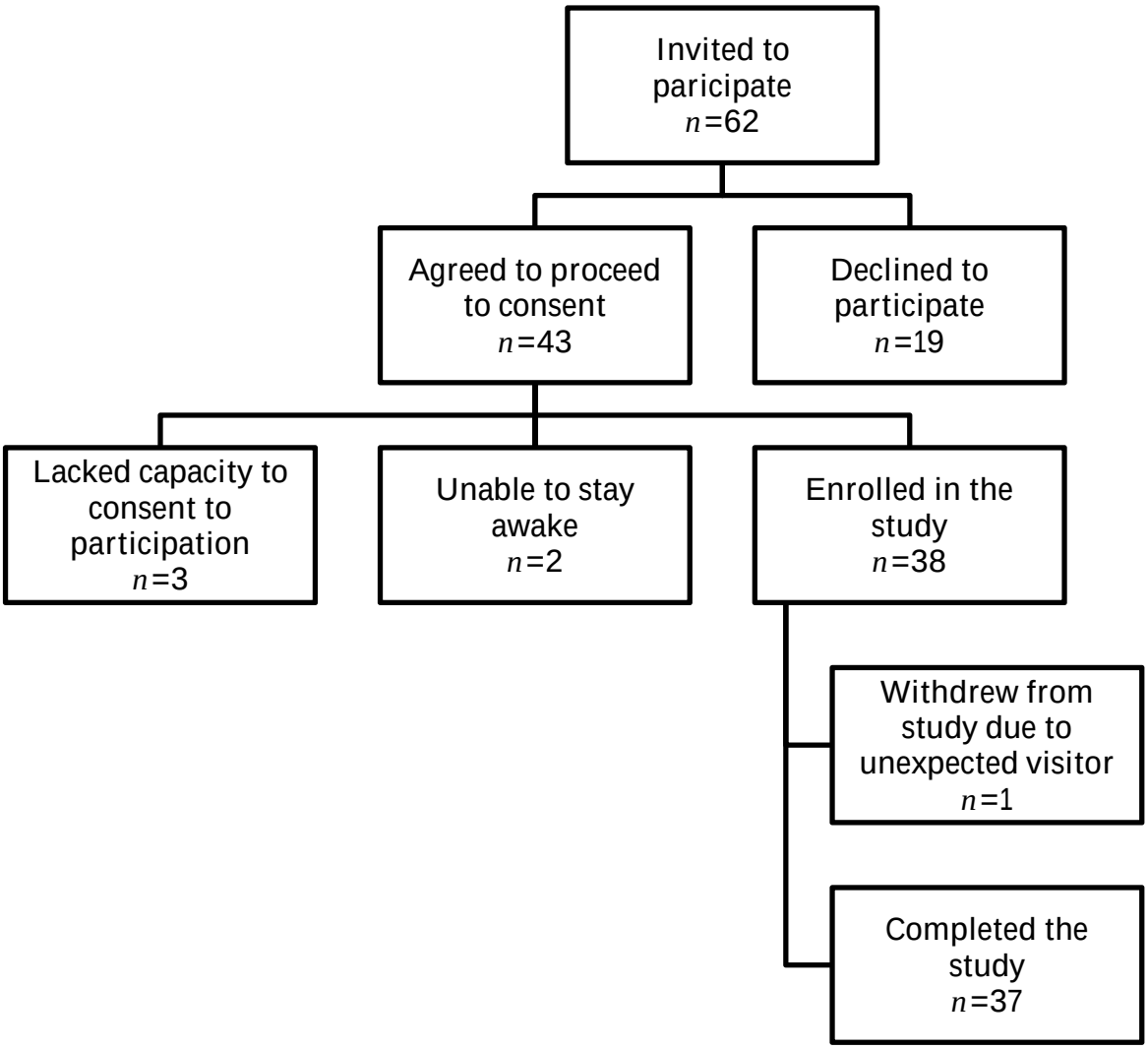

Figure 3.1. Subject Recruitment Flow Chart

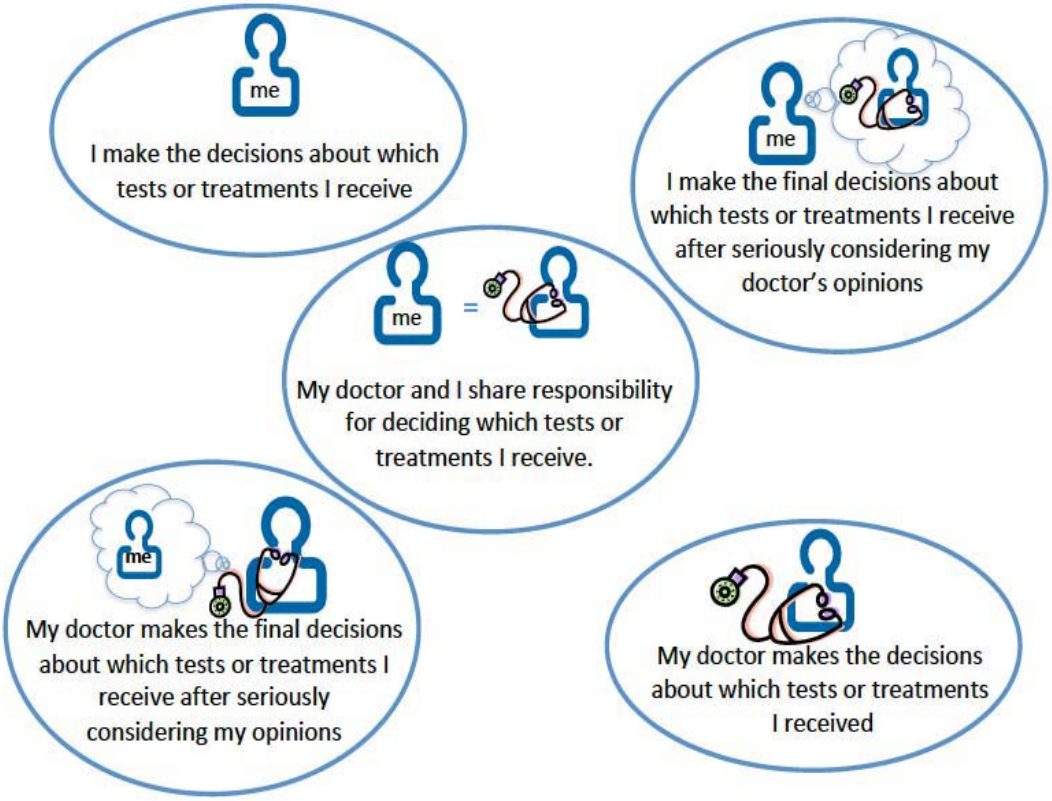

Figure 3.2: Visual Representation of CPS Item

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CHAPTER 4

USING SUPPORTED DECISION-MAKING TO ACHIEVE THE ETHICAL OBJECTIVES OF INFORMED CONSENT FOR INDIVIDUALS WITH IMPAIRED COGNITIVE FUNCTION

Introduction

The Washington Post story opened, "In a victory for the rights of adults with disabilities, a judge declared Friday that a 29-year-old woman with Down syndrome can live the life she wants, rejecting a guardianship request from her parents that would have allowed them to keep her in a group home against her will" (Vargas, 2013). Although Jenny Hatch was a young woman, the court's ruling may influence how medical treatment decisions are made for adults with impaired decisional abilities across all ages and across intellectual, cognitive, and psychosocial disabilities.

Adults have ethical and legal rights to make their own healthcare decisions; these rights are anchored in the legal presumption that all adults have the capacity to make their own healthcare decisions. Some adults, however, have cognitive, emotional, or psychological impairments that affect their ability to make healthcare decisions. When an adult is fully unable to engage in decision-

making (for example, a person in a coma) healthcare decisions will necessarily be made by surrogate decision-makers on behalf of the adult, in accordance with an advance healthcare directive, or a combination of the two. There are few alternatives for addressing decision-making, so these cases are reasonably straightforward.

The hard cases are those when a person is affected by disability such as those caused by neurodegenerative diseases, traumatic or organic brain injury, or other accident or illness that impacts healthcare decision-making abilities, but does not render the person fully unable to participate in the decision-making process. This article focuses on the cases that involve adults whose decision-making ability is in the gray area because they retain some abilities but have a level of impaired function that raises concerns about their ability to provide informed consent for treatment or treatment refusal. The article contains a description of a research and policy agenda that would support the development of a high-quality system of supported decision-making for individuals with impaired decision-making abilities as an alternative to the current system, which relies on surrogates to make decisions on behalf of individuals with impaired decisional abilities.

The Legal Standards Paradigm

Background

The assessment of healthcare decision-making capacity arises in the context of the ethical and legal obligation to obtain informed consent from an individual prior to providing medical treatment. The purpose of informed

consent is to enable patients to make knowledgeable, autonomous decisions about medical tests and treatments. Underlying informed consent doctrine is the view that patients are in the best position to decide what treatment is right for them.

Capacity: The Balancing Point Between Autonomy and Beneficence

There is widespread agreement that, for consent to be valid, an individual must have the capacity to make healthcare decisions. Providers should consider the decisional capacity of their patients, either explicitly or implicitly, during every health care encounter (Appelbaum & Grisso, 1988). There is a heightened obligation to evaluate capacity when there is reason to suspect impairment, such as a diagnosis that would affect judgment or other cognitive function. Healthcare decisions that require consent range from simple diagnostic procedures to the most fundamental and personal decisions in life, including choices affecting the timing and circumstances of death.

To make capacity determinations, providers must make "judgments about patients' interests based on applications of the values of autonomy and beneficence" (Grisso & Appelbaum, 1996, p. 169). Kasser and Ryan (1999) defined autonomy as "volition – the sense that one's behavior emanates from and is endorsed by oneself" (p. 937). Although volumes have been written about autonomy back to the Greek philosophers, this paper will adopt the 1999 Kasser and Ryan definition. An autonomous action could be a major decision about treatment for serious illness or a decision to play bingo without coercion (Kasser & Ryan, 1999). According to the legal standards approach to capacity

assessment, described below in detail, providers are obliged to respect autonomy only when they find that an individual has decisional capacity, because individuals who fail to demonstrate the elements of capacity are "non-autonomous" (Berg, Appelbaum, & Grisso, 1996).

In contrast to autonomy, the ethical principle of beneficence is a "normative … moral obligation to act for the benefit of others, helping them to further their important and legitimate interests, often by preventing or removing possible harms" (Beauchamp, 2008, p. 1). Behind this normative obligation is "a family of overlapping virtues" (Ashcroft, 2007, p. 22), including kindness, generosity, loyalty, altruism, love, and "readiness to render effective help to others in an emergency" (Beauchamp, 2008, p. 2). As typically characterized in the capacity assessment literature, beneficence justifies a suspension of the right to autonomy. Appelbaum and Grisso (1988), for example, described the process of capacity assessment in a 1988 publication as a balance between autonomy and beneficence, defined in this case as protection against "bad decisions"; nearly 20 years later, Appelbaum (2007) still described the process of capacity assessment as balancing autonomy against protection.

The legal standards paradigm developed by Appelbaum and Grisso, building on the earlier work of Roth, Meisel and Lidz (1977), created an operational definition for the point on the spectrum of decisional capacity where autonomy outweighs beneficence. According to the paradigm, people have the capacity to provide informed consent to treatment when they can demonstrate four capabilities: the ability to communicate a choice, understand relevant information, appreciate the situation and its consequences, and reason about

treatment options (Appelbaum, 2007). Appelbaum and Grisso developed the MacArthur Capacity Assessment Test for Treatment to measure patients' capacity and identify those patients who would, under the legal standards paradigm, be judged to lack decisional capacity.

A seminal article by Berg, Appelbaum, and Grisso (1996) explained the origins of legal standards definition of capacity, which was derived primarily from an extensive review of state statutory and case law, commentary, and ethics literature. The four criteria were derived from criteria considered by courts, or under statutes, in cases where an individual's ability to make a decision – sometimes medical, sometimes concerning mental health treatment, and sometimes in an entirely different domain such as the capacity to stand trial – was in question. Scholars drew from areas other than the capacity to consent to medical treatment because the doctrine of informed consent and capacity to consent was still evolving when the legal standards approach was being articulated (Meisel et al., 1977; Roth et al., 1977).

The legal standards paradigm and the work leading up to the publication of the 1996 article moved the state of capacity assessment in a positive direction in two respects. In earlier times, both physicians and judges commonly viewed individuals as lacking capacity based on diagnosis alone. The legal standards paradigm adopted a more nuanced approach when it defined capacity in terms of functional abilities, directly linking the concept of capacity and the downstream results of a determination of incapacity to specific demands of the decision-making process and specific abilities. Studies demonstrated that fewer individuals would be excluded from decisions about their care under the

functional approach to capacity (Appelbaum & Grisso, 1995; Grisso & Appelbaum, 1995a, 1995b, 1995c) than the diagnosis-based approach to capacity. Second, the legal standards paradigm acknowledged that whole persons were not incapacitated; rather, patients had or lacked capacity to make particular decisions based on the demands of the decision-making process (Berg et al., 1996). The legal standards approach continues to dominate the decision-making capacity literature and research, as reflected in a comprehensive overview of the current state of capacity assessment by Moye, Marson, and Edelstein (2013).

After a Finding of Incapacity

It is widely agreed that the legal standards paradigm moved the evaluation of capacity in a positive direction, as evidenced in part by its widespread embrace among clinicians, guidelines, and even the ethics literature. Scores of studies have started with the legal standards framework to characterize rates of incapacity by disease and evaluate instruments for assessing capacity. There has been a lack of attention, however, to what happens after an individual is found to lack the capacity to make a particular decision.

According to the legal standards paradigm, the first step after finding impaired decisional abilities is to evaluate whether disabilities can be treated, restoring the person's capacity to make healthcare decisions (Appelbaum, 2007). Individuals should not be excluded from a decision-making process because of a disability that can be treated or overcome, whether due to a medical issue such as low oxygen levels or a sensory disability, such as hearing or vision loss.

Unfortunately, providers are only rarely reminded about this obligation in the capacity assessment literature.

Once a provider has found that a patient lacks capacity to make a decision and has concluded that the illness or disability adversely affecting capacity is not treatable, then the legal standards paradigm directs the provider to find a surrogate to make decisions on behalf of the patient, follow an advance directive, or a combination of the two (Appelbaum, 2007; Reuben et al., 2014). The patient is now viewed as a "non-autonomous [sic]" actor with respect to the decision being made (Berg et al., 1996).

Under the legal standards paradigm, those patients whose capacity is barely adequate to pass a capacity evaluation are viewed as fully autonomous decision-makers. Patients who barely fail a capacity evaluation are not entitled to any say in their medical decisions, without regard to the importance of the decision to their lives or their desire to remain involved in the decision-making process.

Conceptualizing Capacity as a Dichotomous State

The legal standards paradigm emphasizes the need to view capacity as a dichotomous state: Every patient either has or lacks the capacity to make every treatment decision. The paradigm's emphasis on the need for a dichotomous judgment makes sense, given that the source of the legal standards paradigm is case and statutory law. Cases that make it into the law books usually end with a dichotomous judgment, and statutory law, which echoes case law, will in turn be influenced by the emphasis on a dichotomous outcome in case law. The

dichotomous view of capacity is also supported by well-respected ethicists, Brock and Buchannan, in *Deciding for Others (1989)*, one of the most important texts on surrogate decision-making ever published.

From the time the legal standards paradigm was described, however, scholars have raised concerns about the conceptualization and application of its dichotomous structure. In expressing caution about developing instruments designed to provide a dichotomous judgment about capacity, Kapp and Mossman wrote, "Assuming that cognitively impaired persons must fall into this or that bin may be the wrong way to conceptualize their limitations" (1996, p. 88). They suggested that capacity should instead be viewed as a "fuzzy concept" that is "not readily amenable to Aristotelian, either-or specifications" (p. 88). Even if the dichotomous view of capacity is theoretically defensible (it is not the purpose of this paper to prove or disprove the point, rather it will be accepted as true for the purpose of discussion), it may be necessary to set aside the dichotomous view of capacity because actions that follow from the approach may harm the individuals whom the capacity requirement is meant to protect.

The legal standards view of capacity as a dichotomous judgement is represented in Figure 4.1, which shows that, after decision-making ability declines beyond a given point, a person is viewed as having no capacity. Figure 4.1 helps to illustrate three challenges presented by a dichotomous capacity structure. First, there will be unavoidable error because of the difficulty of correctly placing the person on the capacity line. How different are the individuals represented by points A and B from one another? Are the differences meaningful? This challenge is reflected in high error rates found in capacity

assessment studies, discussed below. Second, consensus is lacking about where the capacity line should be drawn. For example, advocates for adults with disabilities might put the line on the far right side of the figure, while family caregivers who fear that poor decisions are being made by a parent with moderate dementia might put the line further to the left side. Third, the dichotomous structure that separates and treats patient A dramatically different from patient B likely under-supports and over-burdens patient A, who is judged to have capacity, and over-supports and under-involves patient B, who is judged to lack capacity. It is likely that neither result will be beneficent.

Shortly after the publication of the articles describing and defending the legal standards paradigm, a number of scholars voiced concerns (Kapp & Mossman, 1996; Kirk & Bersoff, 1996; Slobogin, 1996). More recently, the capacity assessment literature itself has acknowledged the challenge of applying a dichotomous standard (American Psychological Association, 2008).

A publication by the American Psychological Association and the American Bar Association acknowledged the tension that arises when capacity is judged as a "'binary' or 'dichotomous' state" when it operates in practice "as more of a continuous variable" (American Psychological Association, 2008, p. 28). The publication included a figure that visually represented "clinical capacity" as a continuous variable, and "capacity judgment" as a dichotomous variable. The publication, written for psychologists evaluating capacity for guardianship proceedings, directed psychologists to "consider all the data and offer an opinion as to whether the data, considered in the context of values, risks, and

enhancements, lean more in favor of or against the person's capacity" (p. 29) and to offer a "clear opinion" about capacity.

In an empirical study published in 1997, five physicians who were specialists in geriatric psychiatry, geriatric medicine, and neurology were asked to rate the capacity of patients with mild Alzheimer's disease. These were patients who would hover around the capacity line in Figure 4.1. The physicians agreed that a patient had or lacked capacity only 56% of the time (Marson, McInturff, Hawkins, Bartolucci, & Harrell, 1997). In a later intervention study, five similarly experienced physicians were trained in the legal standards for assessing capacity prior to evaluating capacity of patients with mild or moderate Alzheimer's disease. The mean agreement among physician judgments increased to 76%, although agreement among physicians on the appreciation standard was 67%, and in 12% of the cases the physicians did not even agree with one another about whether the participants had evidenced a choice (Marson, Earnst, Jamil, Bartolucci, & Harrell, 2000). Although findings in the second study were characterized as showing "significant agreement" after physicians were trained on the legal standards, there has not been a serious conversation about whether a system that results in one in four people being misjudged by a small group of experts is an acceptable error rate when the result of that determination is the loss of fundamental rights. In practice, even now, agreement among physicians may be even lower than the 56% reported in the study described above. In contrast to the physicians participating in the Marson study, most physicians who care for older patients with impaired decisional abilities are not geriatricians

(Landefeld, Callahan, & Woolard, 2003), geriatric psychiatrists, or neurologists, and few physicians receive training in capacity assessment.

Volicer and Ganzini found evidence of widespread misunderstanding among physicians about decisional capacity, including wide variation in the criteria for assessing capacity that were considered by providers who conduct capacity assessments, including psychiatrists, geriatricians, and chairs of VA Medical Center Ethics Advisory Committees. Particularly troubling was the fact that half of the providers responding to a poll selected "making decision that seems reasonable" as an element of decision-making capacity, even though reasonableness is not a required element for capacity in either law or ethics (Volicer & Ganzini, 2003). In a related study, providers rated the frequency of concerns about capacity assessment. Ninety-two percent of respondents said that it was common or very common that practitioners do "not understand that capacity (or incapacity) is not 'all or nothing' but specific to a decision." Further, 66% rated as common or very common that "Practioner assumes that if a patient has a diagnosis of Alzheimer's disease or another dementia, even if mild, the patient lacks capacity for making all medical decisions" (Ganzini, Volicer, Nelson, & Derse, 2003, p. 239).

Despite an extensive literature review, the author found no published studies exploring how the misunderstandings described above affect the individuals who are erroneously evaluated as having or lacking capacity under the legal standards paradigm by misinformed providers.

Implications of the Legal Standards Paradigm

Is Routine Exclusion from Decision-Making Beneficent?

Even if it were possible to eliminate all error from capacity determinations, the author has found no evidence that it is a beneficent act to replace those who are found to meet the legal standards definition of capacity with surrogate decision-makers. To the contrary, there is evidence that exclusion may cause harm or fail to promote wellbeing.

Numerous studies have shown that patient involvement in healthcare decision-making is associated with better health-related outcomes across patient populations. In breast cancer treatment, for example, patient participation in decision-making is associated with higher satisfaction with care, better provider compliance with quality measures, and improved patient quality of life (Maly, Umezawa, Leake, & Silliman, 2004). In view of a growing body of evidence that supports patient involvement in care decisions, the Institute of Medicine in 2001 called for patient-centered care (IOM Committee on Quality of Health Care in America., 2001). The VA has adopted the Chronic Care model, based on the premise that "good quality chronic care is characterized by productive interactions between informed and activated patients and a prepared, proactive health care team" (Rodriguez, Appelt, Switzer, Sonel, & Arnold, 2008).

There is no evidence for a defined point in the progression of cognitive decline associated with Alzheimer's disease, for example, where excluding a person who wants to participate in decisions is a beneficent act. However, there would be widespread agreement that there are many specific instances where it would be beneficent to honor a specific request. For example, few people would

endorse honoring the request of a patient who is declining an intervention that would achieve the patient's goals of care because paranoia related to Alzheimer's disease makes the patient fear all medical treatment. The legal standards paradigm does not, however, confine the recommendation that surrogates be substituted as decision-makers in such cases. Rather it categorically recommends substitution by a surrogate in every case where a patient is found to fail to meet the legal standard for capacity.

While there is no evidence that replacing a person who fails to meet the legal standard with a surrogate is beneficial to a person with impaired capacity, there is evidence that individuals with dementia retain sufficient awareness to know when they are being excluded from their care decisions, and on average, they do not want to be excluded. Individuals with dementia reported in one study that they felt left out of the process of planning for their care (Brod, Stewart, Sands, & Walton, 1999), and in another, that they did not have sufficient involvement in decision-making (Cohen, 1991) and did not receive the information they wanted about medical care and support options (Beisecker, Chrisman & Wright, 1997).

Self-determination theory and the stress process model help to explain why excluding individuals from decisions about their care would likely be detrimental. Self-determination theory suggests that autonomy, perception of competence, and relatedness are essential psychological needs that environment and interpersonal relationships can either foster or frustrate (Deci & Ryan, 1985; Ryan & Deci, 2001). When these needs are not met, self-determination theory predicts that poor health, conflict, and distress result (Kasser & Ryan, 1999).

Depriving people of autonomy is associated with poorer measures of wellbeing, while autonomy support, defined as "the extent to which people feel supported in their ability to function autonomously, be choiceful, and make decisions," is related to higher psychological wellbeing among elderly patients in nursing homes (Kasser & Ryan, 1999, p. 938).

Whitlatch, Menne, and Judge have used a modified stress process model to predict the effects of decision-making involvement among older adults with dementia (Menne, Judge & Whitlatch, 2009; Menne & Whitlatch, 2007). The stress process model addresses the role of relationships between care receivers and caregivers, the role of social factors that influence stress in chronic illness, and the role of moderators in making the stress of chronic illness better or worse (Judge, Menne, & Whitlatch, 2010). The research suggests that both the individuals with dementia and their caregivers can benefit when the individual with dementia participates in making routine decisions (Menne, Johnson, & Whitlatch, 2008; Menne, Judge, & Whitlatch, 2009), although the studies did not address treatment decision-making.

Some older adults decline to participate in decisions about their care. In one of the very few studies where older adults with dementia were asked about their preferences for involvement in healthcare decisions, nine percent reported that they would not want to participate in a decision about taking an investigational medication for dementia. The participants who chose not to participate were those whose disease was at the most advanced stage. Although most participants (91%) reported that they wanted to participate in the decisions,

fewer (70%) paired caregivers predicted that the person with dementia would want to participate (Hirschman, Joyce, James, Xie, & Karlawish, 2005).

This body of research casts doubt on the assumption that routinely substituting surrogates for patients deemed to lack capacity is a policy that would produce beneficent results. Even medical associations have recognized that participation is beneficial to patients. Citing Hirschman's study, the American College of Physicians, along with 10 other medical associations, endorsed ethical guidelines that encourage providers to make clinical encounters "patient-centered, allowing for maximum appropriate patient autonomy and participation in decision-making" and to support "patients' ongoing participation in decisions about their care" (Mitnick, Leffler, & Hood, 2010, p. 256).

Supported Decision-Making: An Alternative to Surrogate Decision-Making

The legal standards approach to decision-making capacity assumes that beneficence can be pursued only at the expense of autonomy, and that the two principles are mutually exclusive. That has traditionally been true in contentious legal battles, but it is not necessary in healthcare delivery. While some patients with impaired decisional abilities may assert the right to make irrational decisions, decisions based on untrue premises, or other "bad" decisions that challenge providers, ethics committees, and sometimes even legal departments, a small study of 37 older adults representing a rage of cognitive function (mean MoCA score of 19) suggests that the overwhelming majority of patients, including those who would likely be judged as lacking capacity, want to work with their

physicians and want input from their families or friends in making medical decisions.

It is difficult to come up with a reason why practice would not support these patients' desire to be involved in their healthcare, while providing appropriate support in the decision-making process to address cognitive or other deficits. To do so would be akin to denying a person who cannot walk crutches, instead insisting that others must push her around in a wheelchair, because she is unable to walk without crutches.

For this reason, the dichotomous view of capacity is being replaced with advocacy for supported decision-making. That was the case in *Ross v. Hatch*, Va. Cir. Ct. 2013. Article 12 of the United Nations Charter on the Rights of Persons with Disabilities implicitly adopts supported decision-making when it requires parties to "recognize [that] persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life" and "take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity." Taking a smaller step, but still recognizing the value of inclusion, the Utah Advance Care Planning Act requires surrogates to make decisions "in accordance with the adult's current preferences, to the extent possible" (Utah Code S §75-2A-110), recognizing that even a person who lacks the legal ability to make healthcare decisions independently has the right to have preferences honored. These legal shifts signal increasing awareness that autonomy and inclusion are important, even for individuals with impaired decisional abilities.

Unfortunately, however, there is little guidance on how to encourage participation in care decisions because the emphasis in research on decision-making capacity has continued to focus on dichotomous line-drawing, not on how to involve people in decisions about their care. In 1996, Kapp and Mossman wrote, "By focusing clinical efforts and attention on quantitative assessment of a putative yes-no attribute, a capacimeter may direct attention away from what clinicians can and should do in working with patients whose thinking is impaired" (p. 93). The statement was prescient. Since that time, almost every publication addressing impaired decisional capacity has measured capacity, evaluated the reliability of one or more instruments, considered differences between instruments, or offered reviews of studies of capacity assessment instruments. Kapp and Mossman recommended that efforts focus on a process of "assisted consent," an approach that empowers individuals with impaired decisional capacity by respecting their stated preferences and maximizing relevant abilities. They expressed concern, however, that assisted consent was "in jeopardy of quickly becoming ignored if there is too enthusiastic a rush to quantify and categorize decisional capacity according to standardized test scores" (p. 93).

In nearly 2 decades since those words were published, there has been little to no attention focused on how to identify and address reversible impairments, how to support quality decision-making for individuals with impaired capacity who have been judged to have decisional capacity, or how to involve in decision-making those individuals who have been judged to lack capacity, but who retain

the ability and desire to participate in the decision-making process in some manner.

Lessons from Shared Decision-making

There has been research on ***shared*** decision-making, which is defined as "a collaborative process that allows patients and their providers to make health care decisions together, taking into account the best scientific evidence available, as well as the patient's values and preferences" (Informed Medical Decisions Foundation, 2014, p. 1). Shared decision-making has increasingly been recognized as an effective decision-making methodology that acknowledges "the need to support autonomy by building good relationships, respecting both individual competence and interdependence on others" (Elwyn et al., 2012, p. 1361). Although shared decision-making has been studied primarily in populations of individuals without dementia, it stands in contrast to the legal standards paradigm because it recognizes that decision-making is a collaborative, not solitary, process. Shared decision-making is receiving increasing attention in geriatrics (Milte et al., 2013) because it improves the chances that patients will receive care based on their values and goals (Karel, Moye et al. 2007) especially in circumstances where one treatment is not obviously better than an alternative (Oshima Lee & Emanuel, 2013). Shared decision-making can range from the act of providing publications and brochures or videos to patients, to one-on-one interaction among providers, patients, and their families.

A system of supported decision-making could use concepts already explored in the literature on shared decision-making, but supported decision-

making would require a more comprehensive array of services and policy changes. Supported decision-making would need to start with an assessment of the person's goals and preferences within the decision-making process. For example, an instrument such as the Control Preference Scale could be used to evaluate the person's desired level of participation in the decision-making process in relationship to the provider, but also in relationship to a decision companion, who could be a family member, friend, peer counselor, or even a professional such as a social worker. The second step would match the supports to the person's goals, preferences, and needs. Supports would likely be provided by a multidisciplinary team.

Supported Decision Research Agenda

Although the policy shifts described earlier in this article call for an increased use of supported decision-making, there will need to be research to develop effective, evidence based strategies for supported decision-making.

The first recommendation is that NIH and other federal agencies shift funding away from tools and measurements of capacity designed to produce a dichotomous capacity judgment, and instead fund studies that define the elements of supported decision-making, test approaches to supported decision-making, and define quality in supported decision-making. Of particular concern will be the development of quality assurance procedures to prevent supported decision-making from becoming manipulative or coercive. It will also be important to understand how supported decision-making interventions affect both objective outcomes, such as mortality, medication use, and biological

markers, as well as patient reported measures, such as measures of patient wellbeing.

Another important change in the research agenda would address the exclusion of individuals with impaired cognitive function from research studies. Just as the exclusion of women of child-bearing age from drug trials skewed those results, the exclusion of a substantial percentage of older adults (those with Mini Mental State Examination or Montreal Cognitive Assessment scores below a certain cut point, or those with a diagnosis of dementia or cognitive impairment) will skew the findings of research studies. Perhaps instead of justifying to IRBs why individuals with cognitive impairment should be allowed to participate in studies, researchers should be required to justify their exclusion.

Supported Decision-Making Policy Agenda

The primary policy change that would encourage supported decision-making is a shift away from the legal presumption that patients found to lack the ability to independently make healthcare decisions should be excluded from decisions about their care and replaced by a surrogate decision-maker. That presumption should be replaced with the presumption that a person has the right to choose supported decision-making. Exclusion should be a last resort. Also, because exclusion can impact a person's fundamental right to liberty (for example if the decision is to place the person in a locked rehabilitation facility), people should receive due process protections when their rights are affected. This change will not be easy, because the law governing informed consent and surrogate decision-making is almost entirely found in state law, so these changes

would have to happen in all 50 states and territories.

It is possible, however, to influence care delivery through Medicare and Medicaid law and policy because they fund the majority of healthcare delivered in the U.S. to older adults, as well as younger adults with serious diabilities. Conditions of participation for those programs could require providers to offer supported decision-making to patients found to lack the ability to make informed healthcare decisions without assistance. Those programs could also provide funding for supported decision-making.

Implementing Supported Decision-Making

No law or policy in the U.S. today prevents providers from engaging patients in treatment decision-making, even if the provider has found that a patient's decisional abilities are impaired to the degree that they lack the ability to give informed consent for treatment without support. A provider faced with such a patient should always start by considering whether the reason for impaired ability is treatable or reversible. In some instances, a patient can demonstrate capacity if a physician or nurse or social worker slows down the process of providing the information, carefully breaks the decision-making process into smaller steps, or uses decision-aids (Sugarman, McCrory, & Hubal, 1998). If those steps are unsuccessful, the provider can ask the patient about his or her preferred role in the decision-making process. If the patient agrees to involve a companion to assist in the decision-making process, then the consent process can proceed within the triad. Providers obtaining a signature on an

informed consent form can ask both the patient and the companion to sign the form.

If a patient declines to receive support and the physician does not think treatment can proceed without someone other than the patient providing consent, then other structures, such as social workers who can help to negotiate relatioships, ethics committees, and, as a last resort, legal departments, can be called on to determine next steps. Supported decision-making will not eliminate the need for an adjudication of capacity in some particularly difficult cases, but those cases should be rare exceptions, not the rule.

Kapp and Mossman remarked that a "subtle and nuanced approach to thinking about making medical decisions" is "a concept that the legal system is poorly equipped to accommodate" (1996, p. 93). The healthcare system, in contrast to the legal system, has substantial flexibility to address the subtle and nuanced issues raised when addressing challenges raised when an individual has impaired decisional abilities, and the vast majority of capacity adjudications are made by physicians and other providers, not by the legal system. The legal standards approach to capacity assessment imposes the rigidity of the legal system on the healthcare system, likely to the detriment of the individuals with impaired decisional abilities.

Conclusion

As the healthcare delivery system enters an era where more older adults with impaired decisional abilities are receiving healthcare, and as their rights to remain involved in decisions about their care are increasingly acknowledged,

new, effective strategies will be needed. Evidence hints that such a system could improve the wellbeing of people. At a minimum, it would start with collaboration and respect, rather than the confrontation that a dichotomous approach necessarily involves.

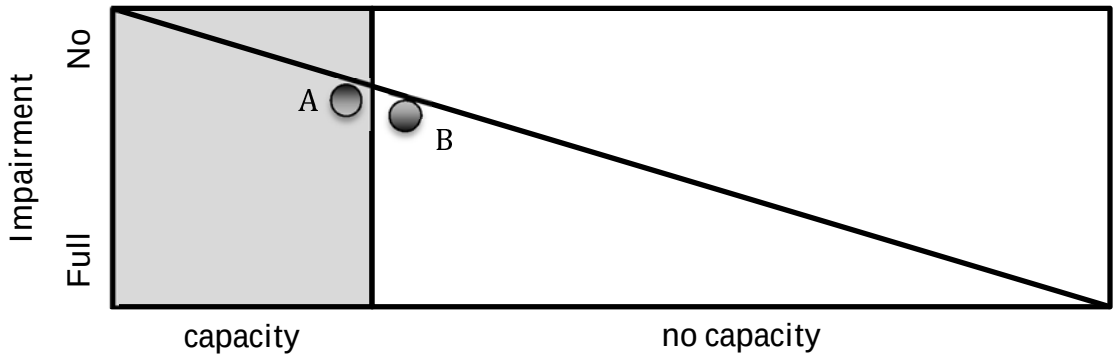

Figure 4.1. Dichotomous Legal Standards Paradigm

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CHAPTER 5

USE OF A MODIFIED CONTROL PREFERENCE SCALE AMONG OLDER ADULTS ACROSS A RANGE OF COGNITIVE FUNCTION

Introduction

The current approach to decision-making capacity neither requires nor encourages clinicians to involve patients in decisions about their care after being judged by the provider to lack the legal capacity to make medical decisions. Providers have been advised to make dichotomous capacity judgments about a patient's ability to make treatment decisions, and, if they judged that a patient lacked capacity, they were directed to seek a surrogate to make decisions on behalf of the patient (Appelbaum, 2007; Reuben et al., 2014; Sessums, Zembrzuska, & Jackson, 2011).

Increasingly, however, state and federal laws, and even an international convention, mandate or encourage providers to include patients with impaired decisional abilities in decisions about their care. The Americans with Disabilities Act (ADA) requires full integration of individuals with disabilities (Americans with Disabilities Act, 1990). The Utah Advance Care Planning Act requires surrogate decision-makers to make decisions "in accordance with the adult's

current preferences, to the extent possible" (Utah Code §75-2A-110), recognizing that individuals who lack the legal ability to make healthcare decisions independently may still choose to be involved in decisions. Article 12 of the United Nations Charter on the Rights of Persons with Disabilities, which is modeled in part on the ADA, requires providers to "recognize [that] persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life" (¶ 2) and "take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity" (¶ 3). Consistent with these mandates, a Virginia court recently refused to exclude an adult with Down Syndrome from participating in her own care decisions, even though she lacked the ability to make those decisions without support in *Ross v. Hatch*, Va. Cir. Ct. 2013.

Despite this changing policy landscape, there is a dearth of research on how to meaningfully and effectively engage patients in decisions about their care. Past research on decisional capacity has largely focused on the question of how to identify those patients who are able to independently make medical decisions (Appelbaum & Grisso, 1995; Berg et al., 1996; Marson & Moye, 2007; Moye & Marson, 2007). This approach to capacity assessment rests on the view that individuals who fail to meet certain standards are nonautonomous (Berg et al., 1996), and that replacing the person with a surrogate decision-maker avoids the risk of a bad decision by an impaired patient (Appelbaum, 2007).

There is evidence, however, that patients with impaired decisional abilities want to be involved in decisions about their care. For example, 92% of patients with Alzheimer's disease expressed the desire to be involved in making a decision

about participation in a study of an investigational medication for Alzheimer's disease (Hirschman, Joyce, James, Xie, Casarett, et al., 2005; Hirschman, Joyce, James, Xie, & Karlawish, 2005).

In a series of studies, a group of researchers examined patient preferences for involvement in decisions about everyday living among older adults with cognitive impairment (Clark, Tucke, & Whitlatch, 2008; Feinberg & Whitlatch, 2001, 2002; Judge, Menne, & Whitlatch, 2010; Menne, Johnson, & Whitlatch, 2008; Menne et al., 2009; Menne, Tucke, Whitlatch, & Feinberg, 2008; Menne & Whitlatch, 2007; Whitlatch, Feinberg, & Tucke, 2005a, 2005b). Across the studies, older adults with impaired decisional abilities were able to report preferences for involvement in daily care decisions, and involvement in decisions is a predictor of quality of life, based on the Quality of Life-Alzheimer's Disease ("QOL-AD") scale, which provides a score representing patients' perspectives on their views on friends, energy, mood, marriage, and ability to do things for fun (Logsdon, Gibbons, McCurry, & Teri, 1999). Combined with the study by Hirschman and colleagues cited above, this body of research suggests the importance of involving older adults with impaired decisional abilities in decisions that affect their lives.

The purpose of this study was to build on prior research by piloting a modified Control Preference Scale (MCPS) to elicit control preferences of older adults with impaired decisional abilities who might be deemed incapable of making treatment decisions due to impaired cognitive function.

Methods

Design

Employing a mixed methods design, this study used a modified Control Preference Scale (MCPS) (Degner et al., 1997; Nolan et al., 2005), and semistructured interviews guided by cognitive interviewing techniques to elicit participants' preferences. Thirty-seven residents of two assisted living facilities and three nursing homes were interviewed one time. Quantitative and qualitative analyses were conducted to evaluate the use of the MCPS in the population. A university IRB approved the study.

Settings and Participants

Individuals were considered for participation if, according to their health record and/or the judgment of facility personnel and/or the investigator, they were age 65 or older and English-speaking, had sensory, physical, and cognitive function sufficient to participate in the interview, and were currently free from active mental illness or chemical dependency.

Consent was obtained by the investigator, an elder law attorney with training and experience in medical ethics, consenting participants for research studies, and evaluating the capacity of adults with cognitive impairment according to a range of legal standards. In addition to reading the IRB-approved consent form to participants, the investigator asked participants to explain, in their own words, the risks and benefits of participation and what study participation would require of them. The investigator considered whether potential participants had the requisite ability to communicate, and to rationally

evaluate, understand, and appreciate the nature of the study, their role in the study, and the risks and benefits of participating in the study (Grisso et al., 1995). For example, a potential participant who was approached was not enrolled when she expressed the desire to help, but was unable to demonstrate an understanding of how her participation would contribute to the study, even after different explanations were provided. Throughout the consent process and interviews, participants were offered the opportunity to stop the interview if signs of physical or emotional distress were observed.

Interviews were conducted in quiet locations selected by the participant, such as conference rooms or the participant's room. In some instances, interviews were conducted in quiet public areas, such as the dining room between meal times, or other areas selected by the participant.

Measures

Descriptive information included age, sex, race/ethnicity, marital status, education, and residential setting, and the relationship with a decision companion. To identify the decision companion, participants were asked to identify a person who would help them to make future medical decisions.

Modified Control Preference Scale (MCPS)

The original version of the CPS (Degner et al., 1997) was used to evaluate participants' preferred role in past and future treatment decision-making encounters. The CPS is a simple and easy-to-administer scale that has been

found to be a valid, reliable, and clinically relevant measure of individuals' preferred treatment decision-making role (Degner et al., 1997).

Both the original and modified versions of the CPS have been widely used in a different patient populations with a variety of conditions, including older adults (Ekdahl, Andersson, Wiréhn, & Friedrichsen, 2011). The original, single-item CPS used a card sort method, but later studies have used a "pick one" approach (O' Donnell, Monz, & Hunskaar, 2007). While the original CPS was used to describe the patient's desired level of control in relationship to a provider in future decisions, later versions modified it to a multi-item measure to allow comparisons of patient preferences for future decision-making to the level of control exercised in past decisions (Singh et al., 2010), and comparisons of the desired level of control by a companion, typically a family member, to the desired level of control by a provider (Nolan et al., 2005).

In this study, both of these modifications were used to elicit participants' preferences about (1A) the role of provider in a past encounter; (1B) the role of a companion in a past encounter; (2A) the preferred role for provider in a future encounter; and (2B) the preferred role for the companion in a future encounter. For example question 2A directed the participant, "Think about a [health care provider's name/type] visit where a decision is made in exactly the way you want." The participant was then shown an illustration of the following five options (shown in Figure 3.2):

1. I prefer to make the decisions about which tests or treatments I receive.
2. I make the decisions about which tests or treatments I receive after seriously considering [health care provider's name/type] opinion.

3. I prefer that [health care provider name/type] and I share responsibility for deciding which tests or treatments I receive.
4. I prefer that [health care provider's name/type] make the final decisions about which tests or treatments I receive after seriously considering my opinion.
5. I prefer to leave all decisions about which tests or treatments I receive to [health care provider's name/type].

The final two items, developed by Nolan et al. (2005), asked the participant to compare the input from the provider and companion:

(3A) When making decisions about your treatment ***right now*** , how do you weigh the input of your doctor and the input of [COMPANION]?"

(3B) If you were ***unconscious and seriously ill***, how would you weigh the input of your doctor and the input of [COMPANION]?"

Participants were asked to choose from the following three responses to questions 3A and 3B:

1. My doctor's input weighs most heavily.
2. My doctor's input and [companion's name]'s input are about equally important.
3. [Companion's name]'s input weighs most heavily.

The complete MCPS is shown in Table 5.1.

The study performed by Nolan et al. (2005) was used as a comparison to the results of this study. The Nolan study was designed to evaluate the decision-making preferences of patients recently diagnosed as suffering from a life-

threatening illness, including cancer, ALS, or congestive heart failure. The mean age of participants was 62.0 (SD = 12.5). The study protocol excluded participants with an adjusted error score of ≥ 5 on the Short Portable Mental Status Questionnaire (SPMQ) (Sulmasy, 2014). Five or more errors on the SPMSQ suggests moderate to severe intellectual impairment, with 3-4 errors suggesting mild intellectual impairment. To adjust the SPMSQ score, one point was subtracted from error score if the subject had only a grade school education, and one point added to the error score if the subject had more than a high school education (Pfeiffer, 1975).

Montreal Cognitive Assessment (MoCA)

To estimate participants' cognitive status at the time of the interview without biasing the interviewer, the MoCA (Nasreddine et al., 2005) was administered after the interview was concluded. Prior testing of the MoCA provided evidence of test-retest reliability (r=.92, p <.001) (Nasreddine et al., 2005), and internal consistency with a Cronbach's alpha of 0.83. For participants in this study with visual or fine motor impairments that prevented full administration of the MoCA, only a subset of the items were completed; a scaled score was used to estimate the total score. The percentage of correct responses to completed items was calculated, and then that percentage of points available for unanswered items was calculated and added to the number of correct responses, yielding an estimate of cognitive status. Nasreddine recommends the following interpretation of MoCA scores, but notes that severity ranges have not yet been established: > 26 = normal range, 18-26 = mild

cognitive impairment; 10-17 = moderate cognitive impairment, and < 10 = severe cognitive impairment (Nasreddine, 2014).

Procedures and Analysis

Data Organization

Questionnaire responses were manually entered into SPSS version 22. To permit comparisons between preferences of participants in this study and preferences reported in the study by Nolan et al. (2005) (with permission from the corresponding author), those results were also entered into SPSS. For the interview data, one researcher organized the text by combining all statements related to decision-making with the provider and decision companion, respectively.

SPSS v. 22 was used to conduct statistical analysis. NVIVO 9 was used to manage and analyze the qualitative data.

Quantitative Procedures and Analysis

Convergent Validity: Comparison with Nolan Results

The analysis tested the hypothesis that control preferences and weight given to input from providers and companions among participants in this study would be aligned with results reported in the study by Nolan et al. (2005), which screened out individuals with moderate or severe cognitive impairment. Although the sample size limited the conclusions that could be drawn from statistical analysis, an analysis that revealed wholly dissimilar results would suggest that the use of the MCPS in a population of older adults with impaired

decisional abilities would lack convergent validity. While not conclusive, aligned responses would provide preliminary evidence of correlation and convergent validity.

For those MCPS items asked of participants in this study and the study by Nolan et al. (2005) (2A, 2B, 3A, and 3B), MCPS preferences of participants were compared. Demographic characteristics for participants in both studies were reported to enable a comparison of the study populations. The mean age of participants in the two studies was reported and the significance of the age difference between the two populations was evaluated using an independent samples t-test. Response distributions for the respective study populations were graphed to allow a visual assessment of alignment between response patterns. To test the hypothesis that the response patterns would be aligned, Fisher's Exact tests were conducted to identify significant differences between the study populations.

Convergent Validity: Within Subject Correlation

A second approach assessing convergent validity considered within subject responses to related items. MCPS question 3A is a measure of the ***relative weight*** a participant would give to input from a provider and companion in future decisions. MCPS questions 2A and 2B, combined represent the ***relative control*** the participant desires from the provider and companion in future decisions. On their face, relative weight and relative control are closely related, but not identical, constructs. A relative control score (RCS) was created to allow a comparison of the combined result of MCPS 2A and 2B with MCPS 3A.

MCPS question 3A asked participants how they would weigh the input of the provider and companion in a future decision. Response options were assigned a numeric value:

1 = Provider input > Companion input

2 = Provider input = Companion input

3 = Provider input < Companion input

Responses to MCPS items designed elicit participants' control preferences for future decisions (2A and 2B) were assigned values 1 to 5, with 5 representing the highest level of control for the provider or companion within the dyad and 1 representing the highest level of control for the participant. A relative control score was calculated by comparing provider level of control to the companion level of control selected by the participant. The three relative control scores were:

1. Provider control > Companion control
2. Provider control = Companion control
3. Provider control < Companion control

To illustrate, if a participant preferred his provider to make treatment decisions on his behalf (2A $Provider = 5$) but did not want his son to participate in decisions at all (2B $Companion = 1$). The relative control score was 1 because five is greater than 1.

It was hypothesized that a participant's relative control score would be aligned with the response to MCPS 3A because the two represent a closely related construct. To test the hypothesis that the RCS and MCPS3 would be aligned, a Spearman's Rank Order Correlation was calculated.

Reliability: Internal Consistency of 4-Item Control Preference Scale

Internal consistency of the four MCPS items (1A, 1B, 2A, 2B) that reflect the construct *Control Preference* in this population was evaluated using a Cronbach's Alpha. An alpha of .80 was considered evidence of internal consistency (Pett, Lackey, & Sullivan, 2003). Although the sample size was too small to conclusively establish reliability, low internal consistency would suggest unreliable responses.

Qualitative Analysis

Triangulation: Narrative Responses

Triangulation of qualitative and quantitative data was used for three purposes: to assess content validity by evaluating participants' explanations of their MCPS responses (Tavernier, Totten, & Beck, 2011), to obtain a more complete understanding of participants' decision preferences, and to evaluate whether participants thought the MCPS effectively captured their preferences. Semistructured interview questions based on cognitive interviewing techniques (Willis, 2005) were used to elicit narrative responses from participants about their decision-making preferences and understanding of the MCPS. For example, participants were asked to describe their preferences for control in their own words.

A coding template based on the MCPS interview questions was created. The portion of the template relevant to this portion of the analysis is shown in Table 5.2. The coding template was systematically applied to the transcripts, and

open coding was conducted to capture any data that may have been missed in the initial template development. Low inference codes were used to describe participants' views of their role in the treatment decision-making process. To establish credibility of the coding, two researchers independently coded the data, then discussed coding results to reconcile differences.

One of the researchers then compared the text coded with template codes (e.g., "describes decision preferences, provider/future") and compared the MCPS responses to the narrative descriptions offered by participants to identify any instances where the MCPS response was inconsistent with the narrative. Exemplar quotes were selected to illustrate the codes, and the second researcher affirmed that the selected text represented the code.

Results

Demographics

A total of 62 individuals were approached. Nineteen declined to participate for a 31% refusal rate (Figure 5.2); reasons for refusal were neither sought nor offered. Among those who began the consent process, three were judged by the researcher to lack sufficient understanding of the study to provide informed consent to participate and two individuals with physical illness (both referred by their physicians) who were thought to have little or no cognitive impairment were unable to stay awake through the consent process. Thirty-eight participants were enrolled in the study, but one withdrew before completing the demographic questionnaire due to a scheduling conflict. Of those who completed

the study, 25 participants were recruited from two assisted living facilities, and 12 were recruited from three nursing homes.

The demographic characteristics of participants are provided in Table 5.3. Half of the participants were over age 82, and 68% were female. Eight percent were members of ethnic or minority groups. While the majority completed high school, 11% had less than a high school education, and 33% were college graduates. Forty-nine percent were widowed, 24% divorced, and the remainder were divided evenly between single and married (13% each).

Three participants declined to begin the MoCA due to pain or fatigue (n=2) or lack of time (n=1). Thirty-eight percent of participants who began the MoCA (13/34) were unable to complete all items due to visual or physical disabilities; their scores were scaled. Participants represented a range of cognitive function: of the 30 possible points on the MoCA, 9% of participants (3/34) had scores at or above 26, suggesting no impairment, 56% of participants (19/34) scored between 18 and 25, suggesting mild cognitive impairment, and the remaining 35% (12/34) scored at or below 17, suggesting moderate to severe cognitive impairment. Results of MoCA scores are reported in Table 5.4.

Validity of MCPS

Convergent Validity: Comparison with Nolan Study Results

Participants' responses to the MCPS were compared to the responses of participants in the Nolan et al. (2005) study. Reported demographic characteristics of participants in the Nolan study are included in Table 5.3. The mean age of participants in this study was 20 years older than the mean age of

Nolan study participants. An independent samples t-test showed that the age difference between the two samples was significant (t=8.9480, df = 165, p < .0001).

Despite differences between the study populations, including age and cognitive function, the distribution of responses to MCPS items 2A, 2B, and 3A were aligned, as shown in Figures 5.3 through 5.5; a Fisher's Exact test did not detect significant differences between the preferences of the two study populations for these three items. For MCPS item 3B, the Fisher's Exact test found a significant difference between the preferences of the participants in the two studies, with a higher percentage of participants in this study valuing the input from the provider and companion equally, and a lower percentage of participants in this study putting more weight on the input from a companion.

Convergent Validity: Within Subject Correlation

Twenty-eight participants answered the three questions used to evaluate inter-item consistency by comparing the RCS to MCPS 3A; results are shown in Table 5.5. Seventy-one percent (20/28) of the paired RCS and MCPS 3A numbers were matched. A Spearman's rank-order correlation was calculated to assess the relationship between RCS and MCPS 3A. Although there was a relationship was in the expected direction, it was not significant, r_s(26) = .347, p = .071.

Quantitative Evidence of Reliability

Internal Consistency (Cronbach's Alpha)

To determine if four MCPS items (1A, 1B, 2A, 2B) represented the construct ***Control Preference*** in the study population, Cronbach's Alpha was used. The scale had an acceptable level of internal consistency in the study population, as determined by a Cronbach's alpha of 0.764. This result suggests that the four MCPS items were measuring the same, or a closely related, construct.

Qualitative Evidence: Triangulation

Logical Consistency Reliability

As reported above, 20 of 28 participants responded to the two MCPS items that made up the Relative Control Score (preferred level of control desired from provider and companion, respectively) in a pattern that was identical to the pattern they chose for MCPS 3A (weight of input from provider and companion, respectively). Two of 28 participants responded in a manner that suggested a violation of the rules of deductive logic (e.g., more control desired from provider, but greater weight given to companion), with the remaining six responding in a manner that neither supported nor undermined the reliability of their responses.

Cognitive Interviewing Findings

Most participants offered a narrative explanation of preferences, in addition to their responses to the MCPS. Text generally supported, explained, or clarified participants' choice of MCPS options.

Provider/Participant Roles in Future Decisions

Participants who selected assertive options on the MCPS questions concerning the role of the providers provided explanations supporting their choices. For example one said, "He knows more than I know about it. So I want his intake, but I still make up my own mind." Another explained, "I would discuss it with him but the final decision would be mine, as I said, as long as I'm compos mentis." A third said, "I always make my own decisions. Nobody decides for me."

Those participants who wanted to share decision-making described that preference. For example, one explained:

> We ought to make the decision together, I think. The doctor and me ought to make the same decision out of the same problem, instead of just being on one side. We ought to both make the decision for what we need to do. Just one of us shouldn't be right. We ought to look at the examples, look at the final decision, then make the final decision together.

Another said, "I believe [the option representing a shared decision-making] would have to be it. I mean, if you didn't both believe in it, why are you there?" A participant who selected a passive role with respect to her provider explained, "The doctor makes the decisions. He tells me what was right."

Companion/Participant Roles in Future Decisions

Participants offered explanations for their preference for a more active role in decision-making when compared to the roles they wanted for decision companions. One participant explained that she wanted her daughter to have a limited role in decisions, "Sometimes I don't like [my daughter's] way of…. The way I want I things done and the way she wants things done are two different

things." Another affirmed her relationship with her daughters, but still wanted their role in decision-making to be limited: "They… we talk on the phone, you know. But I don't depend on them to make the decision…. My daughters don't have much say." Other explanations were categorical: "Q: *Now think about your son*… A: The only person who makes the final decision is my doctor." One participant denied that her companion had any role in decision-making: "No, I don't think my daughter has anything to do with making my decisions." In response to a follow-up question, "*Ideally, do you want your daughter involved in making decisions, while you're still able to make your own decisions?*" she replied, "Not especially. She and I have different points of view, which I'm coming to realize slowly."

Participants also explained preferences for sharing responsibility for decisions with a decision companion, usually one or more children. In response to the question, "*You and your daughter share responsibility?"* one participant *replied*, "We usually do. I value her." Another explained that her children participate in decision-making, "Because they've got brains, I mean, and education, and a lot of things."

There was very little text related to the choice of a passive role in decision-making. In explaining the role of her daughter, one participant said, "My daughter makes them [health care decisions], and I agree with them." One participant who selected a passive role, but had made earlier statements suggesting she wanted an active role in decision-making, explained:

A. I think I would let them make the decision.

Q. *Is that what you want? Or is that what happened in the past.*

> A. Well I'm old... if it happened it happened. I didn't want to leave any bad feelings with them when I go. [Pause]
>
> Q. *So it's better to go along with it than to...*
>
> A. Fight it. They might know better than I know.

Evidence of Unreliable MCPS Responses

Researchers found no evidence that MCPS responses were unreliable. The coding template included the code, "Stated preferences are inconsistent with MCPS responses" but no text was appropriate for this code; when participants explained their responses, their explanations were congruent with their selection of MCPS options.

Rejecting MCPS Choices

Some participants did not find an MCPS option that reflected their experiences. For example, one participant rejected the shared decision-making option, then, when offered, "I prefer that my doctor make the final decisions about which tests or treatments I receive after seriously considering my opinion," replied:

> It doesn't quite describe it because I will tell the doctor what conditions I feel, and the doctor approves of or he knows what they are. He checks me enough to know what they are. And then we just both agree on what should be done. He agrees on what should be done. Or he says what should be done, and then I agree on it.

Another participant did not perceive distinctions between MCPS choices offered:

> Q: [After reading MCPS 2A, then pause] Generally speaking, would you prefer that you and the doctor share responsibility for which tests or treatments you receive?

A: Yes.

Q: Or would you want to make the final decision after seriously considering the doctor's opinion?

A: Well I sort of wind up making the final decision anyway.

Q: Do you see a difference between those two options?

A: Not really.

Discussion

This study was designed to evaluate the validity and reliability of the MCPS to elicit preferences for decision control among individuals across a range of cognitive function. This study provides preliminary support for the use of the MCPS to capture decision-making preference of older adults, even those with impaired cognitive function.

The distribution of preferences across four MCPS items was highly aligned with the preferences of a younger and less impaired study population of patients facing terminal illness (Nolan et al., 2005), which is evidence of convergent validity. A direct comparison of cognitive status between the study populations was impossible because the SPMSQ used by Nolan et al. (2005) could not be compared directly to the MoCA results in this study, and the SPMSQ results were not reported. Both studies, however, used instruments that have been shown to be valid and reliable instruments for distinguishing among individuals with no cognitive impairment or cognitive impairment, versus individuals with scores suggesting moderate to severe impairment. It is likely that participants in the Nolan study had lower prevalence rates of even mild dementia, because prevalence rates are much lower among adults at or below the mean age of that

study's participants than they are in a group of older adults with much higher mean age ("2012 Alzheimer's disease facts and figures," 2012).

The reliability of participants' responses was suggested by the finding that 71% percent (20/28) of participants selected responses across three MCPS items that represented logically consistent choices, although the correlation was not significant. The Cronbach's alpha evaluating reliability within a four-item MCPS representing control preference demonstrated internal consistency. Only two of 28 participants responded to the three questions in a manner that was illogical. Finally, participants' narrative explanations of their preferences, offered in response to cognitive interviewing questions, affirmed the relationship between the preferences they articulated and their selection among MCPS options, supporting the reliability and construct validity of the MCPS in the population of individuals represented by the study participants.

Although some participants struggled with the MCPS, most easily selected among options and affirmed that the MCPS accurately captured their view of the relationships within the decision-making process. These findings support the use of the MCPS in future research studies with this population and in clinical settings, especially if it is paired with an open-ended question to elicit aspects of a person's preferences that might not be captured by the instrument.

Although most participants faced challenges affecting one or more cognitive domains, past research suggests that they have the ability to consistently articulate their values and preferences (Menne, Tucke, et al., 2008). This study, though small, builds on the evidence cited in the introduction that

patients across a range of cognitive function can articulate their preferences for treatment decision-making.

Study Limitations

The study's small sample size was its most substantial limitation. In addition, the study population was not necessarily representative of all older adults, since it was not ethnically diverse, it represented only facility-dwelling individuals, and it was a highly educated group of people. The study sample could also reflect selection bias, since about one-third of those invited declined to participate, and individuals invited were referred by facility employees who could have excluded individuals for reasons other than their failure to meet inclusion/exclusion criteria. Another limitation was the need to use a scaled MoCA total score due to the high level of sensory and fine motor disability among study participants. Finally, the study population did not represent the full range of individuals with cognitive impairment, because participation required participants to have the cognitive ability to consent to participation. It was therefore not able to find a floor for the ability to use the MCPS.

Future Studies

Although participants were not screened for the ability to specifically make medical decisions, many would likely need support from a provider or companion, particularly if the choice were serious or complicated. Future studies should consider how to help individuals and their companions to navigate the process of medical decision-making in the practical context of limited available

options, limited resources, and complex relationships. Future studies should also evaluate approaches to meaningfully engage individuals with impaired decisional abilities in decisions about their care. Although participants leaned heavily toward engaging with providers, providers may lack the skills, training, and time to meaningfully engage in a supported decision-making process with individuals with impaired decisional abilities. Intervention studies could examine different strategies for meaningful engagement with both the provider and companion.

Conclusion

This study provides preliminary support for the use of the MCPS in eliciting decision-making preferences of older adults across a range of cognitive function for both clinical and research use. To fully honor the preferences of older patients across a range of cognitive function, however, more research is needed to develop and implement strategies for supported decision-making for patients with impaired decisional abilities.

Table 5.1

MCPS Question Series and Response Options

CPS: Provider/past decision				
1	2	3	4	5
I made the decision about which tests or treatments I received.	I made the decision about which tests or treatments I received after seriously considering my doctor's opinion.	My doctor and I shared responsibility for deciding which tests or treatments I received.	My doctor made the final decision about which tests or treatments I received after seriously considering my opinion.	My doctor made the decisions about which tests or treatments I received.
CPS: Companion/past decision				
1	2	3	4	5
I made the decision about which tests or treatments I received.	I made the decision about which tests or treatments I received after seriously considering [NAME]'s opinion.	[NAME] and I shared responsibility for deciding which tests or treatments I received.	[NAME] made the final decision about which tests or treatments I received after seriously considering my opinion.	[NAME] made the decisions about which tests or treatments I received.
CPS: Provider/future decision				
1	2	3	4	5
I prefer to make the decisions about which tests or treatments I receive.	I prefer to make the decisions about which tests or treatments I receive after seriously considering my doctor's opinion.	I prefer that my doctor and I share responsibility for deciding which tests or treatments I receive.	I prefer that my doctor make the final decisions about which tests or treatments I receive after seriously considering my opinion.	I prefer to leave all decisions about which tests or treatments I receive to my doctor.
CPS: Companion/future decision				
1	2	3	4	5
I prefer to make the decisions about which tests or treatments I receive	I prefer to make the final decisions about which tests or treatments I receive after seriously considering [NAME]'s opinion.	I prefer that [NAME] and I share responsibility for deciding which tests or treatments I receive.	I prefer that [NAME] make the final decision about which tests or treatments I receive after seriously considering my opinion.	I prefer to leave all decisions about which tests or treatments I receive to [NAME].
Nolan Questions (NQ)				
NQ: Relative weight between provider and companion/participant involved in decision				
1		2		3
My doctor's input weighs most heavily.		My doctor's input and [NAME]'s input are about equally important.		[NAME]'s input weighs most heavily.
NQ: Relative weight between provider and companion/participant unconscious and seriously ill				
1		2		3
My doctor's input weighs most heavily.		My doctor's input and [NAME]'s input are about equally important.		[NAME]'s input weighs most heavily.

Table 5.2

Coding Template and Open Codes

Template Codes
Description of Control Preferences
Provider/Past Decision
Companion/Past Decision
Provider/Future Decision
Companion/Future Decision
Provider vs Companion Weight/Current Decision (Individual Participating)
Provider vs Companion Weight/Future Decision (Individual Not Participating)
Adequacy of MCPS

Table 5.3

Participant demographics (N=37) compared to Nolan Study (N=130)

Characteristic		Participants	Nolan Study
Age, years (mean ± *SD*)		82 ± 9	62 ± 12.5
Female, *n* (%)		25 (68%)	47 (37%)
Race, *n* (%)			
Hispanic		1 (2.7%)	9 (7.0%)
African American		1 (2.7%)	30 (23.3%)
Other		1 (2.7%)	7 (5.4%)
White		34 (91.9%)	83 (64.3%)
Marital status, *n* (%)			
Married		5 (13.5%)	64 (49.2%)
Single	(Unmarried)	5 (13.5%)	66 (50.8%)
Divorced		9 (24.3%)	
Widowed		18 (48.6%)	
Education, *n* (%)			
≤ High school graduate		10 (27%)	84 (64.6%)
Some college		15 (40.5%)	46 (35.4%)
≥ College graduate		12 (32.4%)	

Table 5.4

Scaled MoCA Scores (N=34)

	Scaled Score *n*(%)
Mean ± *SD*	19.1± 4.9
Range	7, 29
≥ 26 (no impairment detected*)	3 (9%)
18-25 (mild cognitive impairment*)	19 (56%)
< 17 (moderate to severe impairment*)	12 (35%)

* Nasreddine (2014).

Table 5.5

Comparison of Relative Control Scale and MCPS 3A, Weight of Input from Provider Compared to Companion

		CPS Control Score			
		Provider > Companion	Doc = Companion	Companion heaviest	Total
NQ Input Weight Score	Provider > Companion	**8**	2	1	11
	Provider = Companion	3	**12**	0	15
	Provider < Companion	1	1	**0**	2
Total		12	15	1	28

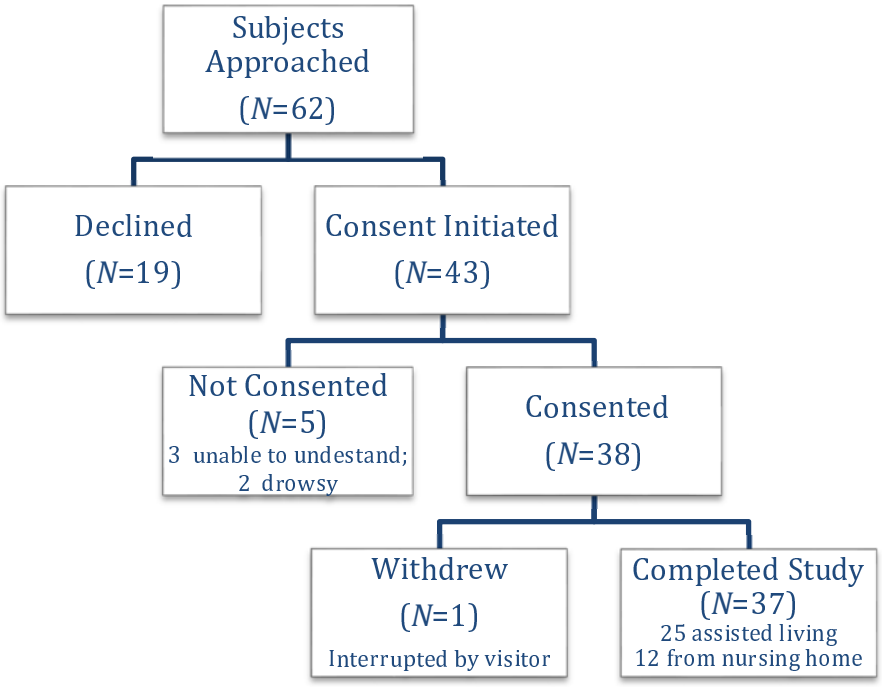
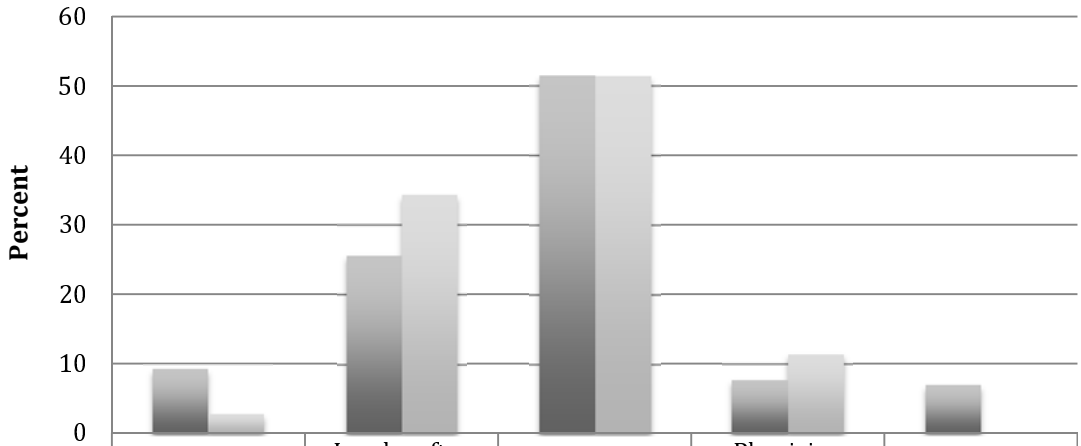


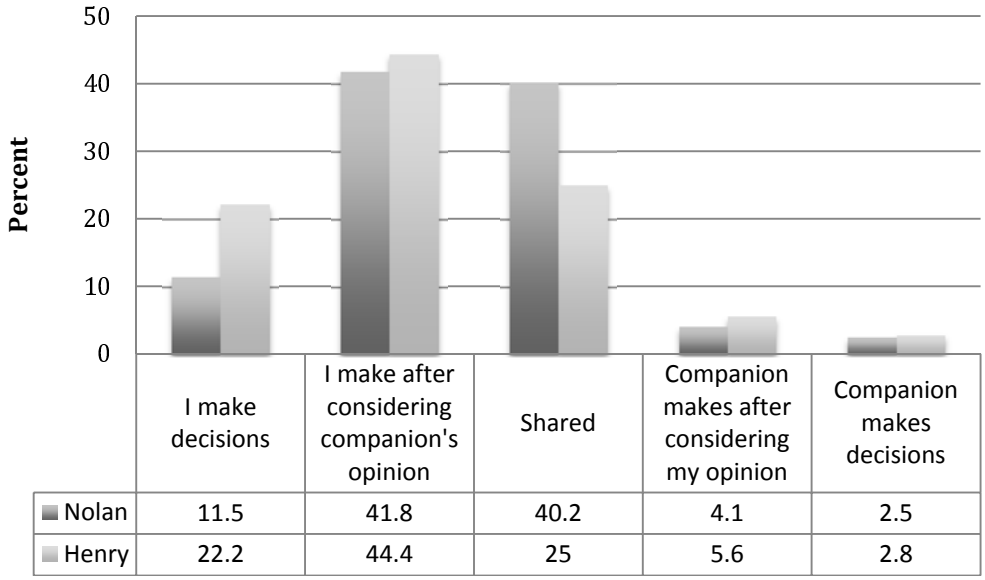
Figure 5.1: Subject Enrollment



	I make decisions	I make after considering physician's opinion	Shared	Physician makes after considering my opinion	Physician makes decisions
Nolan	9.2	25.6	51.5	7.7	6.9
Henry	2.9	34.3	51.4	11.4	0

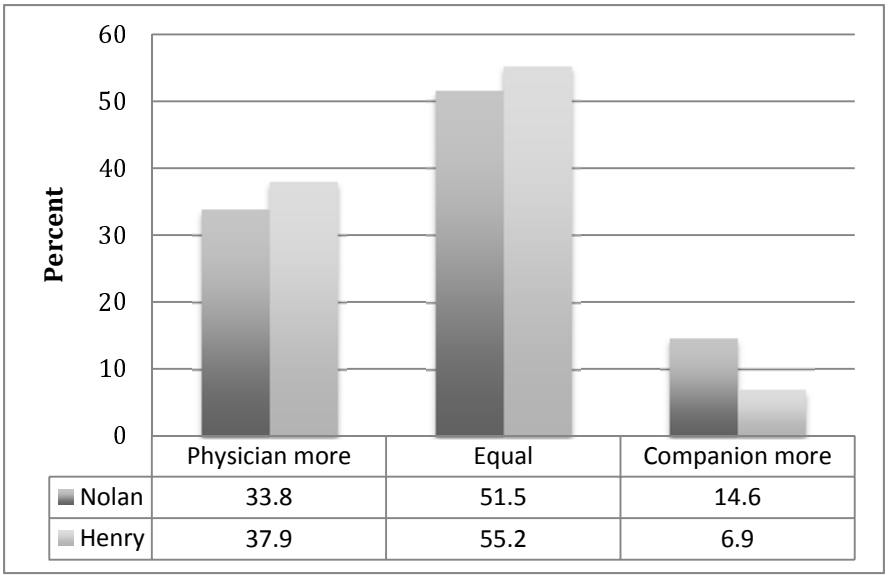
Fisher's Exact Test 4.891, $p = .284$

Figure 5.2: Comparison of Preferences for Provider Involvement (CPS 2A) across Nolan and Henry Studies.



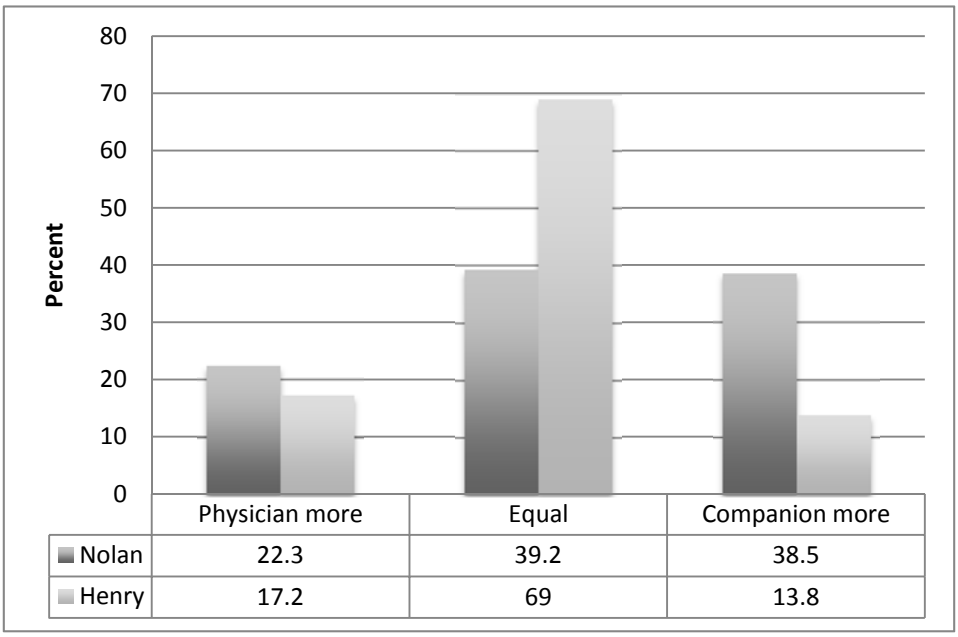
Fisher's Exact Test 5.328, $p = .221$

Figure 5.3: Comparison of Preferences for ***Companion*** Involvement across Two Studies (percentage)



Fisher's Exact Test 1.089, $p = .627$

Figure 5.4: Weight Given to Provider vs. Companion when Participant Involved



Fisher's Exact Test 9.147, p = .009

Figure 5.5: Weight Given to Provider vs. Companion when Participant Not Involved

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CHAPTER 6

DECISION-MAKING PREFERENCES OF OLDER ADULTS ACROSS A RANGE OF COGNITIVE FUNCTION

Introduction

The purpose of this mixed methods study was to describe how older adults across a range of cognitive function characterized their role in a past treatment decision-making encounter and their preferred role in future treatment decision-making encounters. Decision role relationships with both providers and decision companions (in most cases family members) were explored. In addition to evaluating the use of the Control Preference Scale, cognitive interviewing was used to identify elements of decision-making not captured by the CPS.

The treatment preferences of older adults with impaired decisional abilities are largely unexplored. Law, ethics, and clinical practice guidelines view capacity as a dichotomous state: Patients have or lack capacity for treatment decisions. As typically framed, once an individual is found to lack capacity a surrogate decision-maker should be sought to replace the individual as the decision-maker (Appelbaum, 2007; Reuben et al., 2014). Little to nothing is said in practice guidelines or research studies on capacity assessment about any role for the individual who has been found to lack capacity (Appelbaum, 2007;

Appelbaum & Grisso, 1988; Appelbaum & Grisso, 1995; Appelbaum & Roth, 1982; Berg & Appelbaum, 2001; Grisso & Appelbaum, 1995a, 1995b, 1996, 1998a, 1998b; Grisso et al., 1995; Meisel et al., 1977; Roth et al., 1977). The approach assumes that any harm that might occur if individuals who lack capacity were permitted to make treatment decisions outweighs the harm that might result from excluding individuals from their own treatment decisions (Berg et al., 1996b). Increasingly, however, state and federal laws, and even an international convention, mandate or encourage providers to include individuals with impaired decisional abilities in decisions about their care. (United Nations, 2006) ("Advance Health Care Planning Act," 2007) ("Americans with Disabilities Act," 1990).

This study was designed to describe the decision-making preferences of older adults across a range of cognitive function from the perspective of the individual. The results will inform the design of future studies that will help to guide implementation of the policies and laws that increasingly encourage the involvement of all individuals in decisions about their lives, to the degree that they desire.

Methods

This descriptive study used a mixed methods approach to evaluate decision-involvement among older adults representing a range of cognitive function.

Settings and Participants

The investigator recruited participants from three nursing homes and two assisted living facilities. Individuals were eligible to participate if they were aged 65 or older. Facility staff referred individuals who they viewed as having adequate cognitive and physical ability to participate in the consent process and an interview predicted to last about one hour.

Interviews were conducted in quiet locations selected by the participant, such as conference rooms or the participant's room. In some instances, interviews were conducted in public areas, such as the dining room between meal times, or other area of the participant's choosing. Interviews were audiotaped with the consent of each participant.

Mixed Methods

Mixed methods are used to study phenomenon because "different aspects of reality lend themselves to different methods of inquiry" (Sandelowski, 2000, p. 247). Health care decision-making is a very complex interaction between patient and provider, and in the geriatric population, the complexity is frequently compounded further by the presence of one or more individuals such as an appointed health care agent, family member, or friend (Kapp, 1991). This complicated interaction is most effectively described and clarified by examining the interaction from different perspectives using a combination of research methods to develop a more accurate description of reality (Foss & Ellefsen, 2002).

Measures

Demographic data acquired during the interview included age, sex, race/ethnicity, marital status, education, and residential setting, as well as the relationship with a decision companion, defined as a person the participant identified as being involved in past and future decision-making encounters. In order to provide a past decision-making encounter that would serve as a point of reference, participants were asked to describe a past decision-making process in which they had accepted or rejected medical treatment ("target encounter").

Satisfaction with Decision Scale (SDS)

Participants evaluated the decision-making process that occurred during the target encounter using the Satisfaction with Decision Scale (SDS), a short and easy-to-use instrument designed to measure satisfaction with elements of decision-making, such as the degree to which the decision-making process contained elements of an effective decision-making process (O'Connor, 1995), and satisfaction with participation (Holmes-Rovner et al., 1996). Reliability was demonstrated with a Cronbach's alpha of .86 (Holmes-Rovner et al., 1996). The SDS has been used extensively, including a recent study involving older adults with dementia (Carmody et al., 2014).

Control Preference Scale (CPS)

The Control Preference Scale (CPS) (Degner et al., 1997) was used to evaluate participants' perception of their role in the target encounter and their preferred role in future decision-making encounters. The first generation of the

CPS was a single item, card sort instrument used to evaluate the patient's preference for control within the patient/physician dyad. It was found to be a valid, reliable, and clinically relevant measure of individuals' preferred decision-making roles (Degner et al., 1997). A number of later studies used the CPS to describe individuals' perception of their roles in past decision-making encounters (Jasvinder A. Singh et al., 2010). The scale has been widely used in different populations with a variety of conditions, including older adults (Ekdahl et al., 2011), although the author did not locate any other studies that used it to evaluate the preferences of a population that includes individuals with impaired cognitive function.

Further expanding the CPS, Nolan and colleagues (2005) used the CPS framework to explore control preferences within the patient/companion (typically a family member) dyad. They also extended the CPS to investigate how the preferences within the patient/physician and patient/companion dyads changed when patients were asked how they would weigh the respective input between the physician and companion (1) when the patient is involved in the decision and (2) when the patient is unconscious and seriously ill, and consequently fully unable to participate in the decision-making process.

Participants were asked first to describe their decision-making role with respect to their physician for a past decision and then about the same decision with respect to a decisions companion (generally a family member). Participants were then asked about their preferred decision role with respect to the physician and decision companion (Table 6.1).

In this study, a modified CPS was used to elicit:

Past encounter

1A Participant's reported level of control within the participant/***physician*** dyad in a ***past*** decision-making encounter

1B Reported level of control within the participant/companion dyad in a ***past*** decision-making encounter

Future encounter:

2A Preferred level of control within the participant/***physician*** dyad in ***future*** decision-making encounters

2B Preferred level of control within the participant/***companion*** dyad in ***future*** decision-making encounters

Relative weight of input in future encounter:

3A Weight given to respective input from the physician and companion in a future decision-making encounter ***involving the participant***

3B Weight given to respective input from the physician and companion in a future decision-making encounter that occurs at a time when ***the participant is unconscious and seriously ill and is fully unable to participate***.

For questions 1A to 2B, participants selected one of five options that best represented the past or preferred future decision-making role. For example, the choices for MCPS 2A (future/physician) were:

1. I prefer to make the decisions about which tests or treatments I receive.
2. I prefer to make the decisions about which tests or treatments I receive after seriously considering my doctor's opinion.

3. I prefer that my doctor and I share responsibility for deciding which tests or treatments I receive.
4. I prefer that my doctor make the final decisions about which tests or treatments I receive after seriously considering my opinion.
5. I prefer to leave all decisions about which tests or treatments I receive to my doctor.

For MCPA 1A through 2B, participants were presented with the five choices represented by drawings on a single page (Appendix A). The three options offered for questions 3A and 3B were

1. My doctor's input weighs most heavily
2. [Companion's] input weighs most heavily
3. My doctor's input and [Companion's] input are about equally important

The six-item series with all response options are shown in Table 6.1.

Cognitive Interviewing

Cognitive interviewing is a qualitative research technique used to evaluate survey questionnaires. Cognitive interviewing techniques are used to "to study the manner in which targeted audiences understand, mentally process, and respond to [questions] ... with a special emphasis on potential breakdowns in this process" (Willis, 2005). Cognitive interviewing techniques were used to consider whether the MCPS accurately captured participants' views of the target decision-making process. In addition, the techniques were used to evaluate whether older adults across a range of cognitive function have the ability to respond to the

questionnaire. Probing questions that elicited participants' descriptions of their experiences and preferences following survey administration allowed the investigator to evaluate whether the survey responses and associated narrative explanations for the responses aligned. Finally, cognitive interviewing was used to identify domains in the decision-making process that were not captured by the MCPS.

MoCA

To estimate participants' cognitive status at the time of the interview, the Montreal Cognitive Assessment (MoCA) (Nasreddine et al., 2005) was administered after the interview was concluded. The MoCA was used (1) to evaluate the range of cognitive status across study participants, and (2) to determine differences in preferences among participants with lower or higher total or subscale MoCA scores. Test/retest reliability for the MoCA has a correlation coefficient of .92, $p < .001$, and internal consistency was demonstrated with a Cronbach's alpha of 0.83 on standardized items (Nasreddine et al., 2005).

Many studies involving individuals with suspected cognitive impairment use the MoCA or a similar cognitive screening instrument as the first study procedure to determine whether participants have the capacity to consent to participation, but cognitive screening instruments are not appropriate for capacity assessment (J. Karlawish et al., 2013; Pachet, Astner, & Brown, 2010). In this study, capacity to consent to participation was assessed as part of the informed consent process.

Some participants were unable to complete some MoCA items due to visual or fine motor skill impairments that prevented full administration. To evaluate relationships between cognitive function and responses to the MCPS, subscale scores were used, with uncompleted subscales excluded from calculations designed to detect correlations. For analyses requiring the total score, a scaled score was calculated to estimate the total score for participants who were unable to complete the MoCA. The scaled score was calculated based on the percentage of points awarded from the points available for completed items was calculated. That percentage of the points available for unanswered questions was then calculated and added to the points received for completed items.

A scaled score is not a perfect method for addressing missing data in the MoCA because the MoCA is comprised of subscales designed to detect impairment in distinct cognitive domains; use of a scaled score could result in under- or over-weighting one of one or more domain. To show the range within which a scaled score could over- or under-estimate the participants' scores, the raw score and the highest score possible (all points were awarded for the subscales not completed) were calculated and reported.

Nasreddine recommends the following interpretation of MoCA scores, but notes that severity ranges have not yet been established: $\geq$ 26 = normal range, 18-25 = mild cognitive impairment, 10-17 = moderate cognitive impairment, and < 10 = severe cognitive impairment (Nasreddine, 2014).

Companion Questionnaire

An on-line questionnaire for use with decision companions was developed to mirror the CPS question series asked of the participants. At the end of the interview, participants were asked if they would consent to having their decision companions contacted to complete that portion of the study. It was emphasized that the participant could decline to involve the companion. During the first 19 interviews, eight of the participants did not consent to involving a decision companion. For the first 10 who consented, two emails each were sent to five companions with links to the on-line survey. One began the on-line survey but did not complete it. The other four did not respond. Two voicemail messages each were left for the other five companions. None replied. At that point, it was decided to terminate that portion of the study.

Medicare Current Beneficiary Survey and
Information Preferences

Questions concerning the role of nonmedical companions in medical appointments from the Medicare Current Beneficiary Survey: Usual Source of Care Questionnaire (2010) were asked. Participants were also asked if they wanted their physicians to give them prognostic information about a range of health outcomes that may be related to a current or future diagnosis.

Data Organization and Processing

Questionnaire responses were manually entered into SPSS version 22; recordings of interviews were used to validate the response recorded on the form

and the data entry. The portions of interview tapes that related to the study objectives, including decision-making preferences and satisfaction with past decisions, were transcribed verbatim. Remarks that were not related to the study objectives (for example the history of a participant's house's architecture, or a daughter's desire for the participant's new shoes) were not transcribed. This approach reduced unnecessary transcription efforts and avoided the transcription of potentially sensitive, but unrelated, data. One researcher organized the text by combining all statements related to decision involvement with the physician and decision companion, respectively. NVIVO 9 was used to manage and analyze the data.

Analysis

Descriptive statistics (frequencies and percentages for categorical variables, means and standard deviations for continuous variables) were calculated for all variables, and additional statistical analyses were conducted with SPSS v. 22.

Coding Narrative Text

A coding template based on the interview questions was created. The coding template was then systematically applied to the transcripts allowing for open coding to capture any data that may have been missed in the initial template development. To establish credibility of the coding template, two researchers independently coded the data, using low inference codes to describe participants' views of their role in the decision-making process. The two researchers discussed

coding results and emerging categories. Exemplar quotes were selected by one researcher to illustrate each code, and then the second researcher affirmed that the selected text represented the code.

Modified Control Preference Scale Analysis

To describe the level of control study participants reported in the ***past*** encounter, frequencies for participants' choices on MCPS 1A (participant/physician) and 1B (participant/companion) were calculated and reported. To describe the level of control study participants said they want in ***future*** decision-making encounters, frequencies for participants' choices on MCPS 2A (participant/physician) and 2B (participant/companion) were calculated and reported. To describe how participants weighed the relative input of a decision companion and physician during two future scenarios, MCPS 3A (participant involved) and 3B (participant unable to be involved), frequencies were calculated and reported. The analysis of participants' explanations of their MCPS choices was reported, along with exemplar quotes from the interviews. In addition, narrative data describing how participants weighed the input from decision companions and physicians were reported and representative examples of participants' narrative descriptions for the code were reported.

CPS Response Patterns

The Wilcoxon Signed Ranks test was used to evaluate differences between a participant's responses within following MCPS question pairs:

1. Physician past (1A) compared to preferred (2A)

2. Companion past (1B) compared to preferred (2B)
3. Physician past (1A) compared to Companion past (1B)
4. Physician preferred (2A) compared to Companion preferred (2B)
5. Weight of input between Physician and Companion with participant involved (3A) compared to weight of input with participant unconscious and seriously ill (3B).

Relationships Between MoCA Scores and CPS Responses

Spearman's Rank Order Correlation was used to identify correlations between MoCA scores (total and subscales) and CPS responses. It was hypothesized that, consistent with one past study (K. B. Hirschman, Joyce, James, Xie, & Karlawish, 2005), participants with the lowest MoCA scores would adopt the most passive roles in the decision-making process.

Decision-Making Characteristics Not Captured in CPS

To describe characteristics of the decision-making process that were important to older adults across a range of cognitive function but were not captured in the CPS, the qualitative analysis described above was conducted. Codes were reported and exemplar quotes provided.

Human Subjects Protection

The study protocol was approved by the University of Utah Institutional Review Board. The study was designed to include older adults with impaired cognitive function, a group that is considered to be vulnerable. Under the

protocol, the interviewer reviewed the consent document with a participant, engaging the participant in a discussion about the study and about how the participant understood the study protocols, benefits, and burdens. All of the participants who were enrolled in the study were judged to have understood the nature of the study and the requirements of the study, and all participants consented to participation. Although the approved protocol allowed consent to be obtained from a legally authorized representative when the participant was viewed as being unable to provide informed consent, the investigator concluded that those participants who lacked the ability to understand the study were also unable to effectively participate in the cognitively demanding interview process.

Results

Sample

A total of 62 individuals were approached. Nineteen declined to participate for a 31% refusal rate. Among those who began the consent process, three were judged by the researcher to lack sufficient understanding of the nature of the study to provide informed consent to participate and two were unable to stay awake through the consent process. Thirty-eight participants were enrolled in the study, but one withdrew before completing the demographic questionnaire due to an unexpected visitor. Of those who completed the study, 25 participants were recruited from two assisted living facilities, and 12 were recruited from three nursing homes.

The demographic characteristics of participants are provided in Table 6.2. Half the participants were over 82, and 68% were female. Eight percent were

members of ethnic or minority groups. Thirty-three percent were college graduates, and 11% had less than a high school education. About half were widowed, and 24% were divorced, with the remainder divided evenly between single and married.

The relationships between participants and the decision companions they identified are reported in Table 6.3. A majority of participants (n=27) named one or more adult children as a decision companion. Among five participants who named a spouse as the decision companion, all spontaneously named alternate decision companions including one or more children (n=4) or a nephew (n=1). Other participants named siblings, friends, or facility staff as primary or secondary decision companions.

Cognitive Status

Among the 37 participants, 8% did not start the MoCA (3/37), and 35% (13/37) were unable to complete all of the MoCA subscales due to visual or motor impairments. Based on a scaled score, participants who started the MoCA represented a range of cognitive function: 9% of participants (3/34) scored at or above the score where no impairment is detected, 56% of participants (19/34) scored in the range suggesting mild cognitive impairment, and the remaining 35% (12/34) scored in a range suggesting moderate to severe cognitive impairment. The study population represents a range of cognitive function, whether the scaled score, raw score, or highest possible score were used, as shown in Table 6.4.

SDS

Frequencies of SDS responses are reported in Table 6.5. About two-thirds of participants who responded to one or more SDS items responded "agree" to all six items.

Control Preference: Physician Past (1A) and Preferred (2A)

In response to MCPS 2A (preferred role for the physician), about half of the participants (18/35) wanted to share decision-making with the physician in future treatment decisions, while about a third (12/35) wanted to make the decision themselves after seriously considering the physician's opinions. Only one wanted to make treatment decisions without considering the physician's opinions. Four participants wanted the physician to make decisions after considering the participant's opinions, and no one wanted the physician to make the decision without considering his or her opinion. Results are reported in Table 6.6.

Two-thirds of 29 participants who responded to items addressing the physician's role in the past (1A) and preferred role in the future (2A) preferred that the physician's role in future decisions be the same as it was in the past. For the 10 participants who wanted the physician's roles to be different, nine wanted more control in future encounters than they reported having in the past, with only one wanting a physician to exercise more control in future encounters than in the past. The Wilcoxon Signed Ranks Test was conducted to evaluate whether participants preferred more control in future encounters than they reported having in the past. The results showed a significant difference in experienced

past and preferred future decision preference (z = -2.214, p = .04). The mean of the ranks in favor of more control by the participant in the future was 8, while the mean of ranks in favor of more control by the physician was 5.22.

Narrative responses supported participants' MCPS choices. The following examples of text relating to MCPS 2A (participant/physician future) described the preference for an active decision-making role.

> (02) He knows more than I know about it. So I want his intake, but I still make up my own mind.
>
> (23) I would discuss it with him but the final decision would be mine, as I said, as long as I'm compos mentis.
>
> (32) I always make my own decisions. Nobody decides for me.

The following describe a preference for a shared decision-making role:

> (01) We ought to make the decision together, I think. The doctor and me ought to make the same decision out of the same problem, instead of just being on one side. We ought to both make the decision for what we need to do. Just one of us shouldn't be right. We out to look at the examples, look at the final decision, then make the final decision together.
>
> (09) I think the doctor and me together. I want to know what's going on. It's my body and I may be wacky, but I don't think so.
>
> *You and the doctor equally share in the decision?*
>
> I believed that would have to be it. I mean, if you didn't both believe in it, why are you there?

The only participant who preferred to defer decision-making to the physician said, "The doctor makes the decisions. He tells me what was right."

Control Preference: Companion Past (1B) and Preferred (2B)

Two-thirds of participants (24/36) wanted more control over future decisions than their companions, compared to one-fourth (9/36) who wanted to share responsibility for with the companion. Only three participants wanted the companion to have most of the control in future decisions.

Seventeen of the 25 participants responding to MCPS 1B and 2B (companion past and future) wanted the companion's role to be the same in the future as it was in the past. For the eight participants who wanted the companion's role to be different, five wanted more control in future encounters than they had in the past, and three wanted the companion to have more control in future encounters than in the past. The Wilcoxon Signed Ranks Test did not detect a significant difference between the preference for control in the future than the level of control in the past, z = -1.273, p = 0.203.

Participants described their preference for an active role in decision-making when compared with their companions.

> (04) Sometimes I don't like [my daughter's] way of …. The way I want I things done and the way she wants things done are two different things.
>
> (05) They… we talk on the phone, you know. But I don't depend on them to make the decision…. My daughters don't have much say.
>
> (08) *Now think about your son…*
>
> The only person who makes the final decision is my doctor.
>
> (16) *Which would you choose for your daughter's role in a serious decision…* No, I don't think my daughter has anything to do with making my decisions.

(25) As long as I'm able I feel that I make the decisions. I haven't really been in a situation where, you know, I've needed [family members] involved. It's usually me and the doctor.

(30) *Ideally, do you want your daughter involved in making decisions, while you're still able to make your own decisions?*

Not especially. She and I have different points of view, which I'm coming to realize slowly.

Other participants explained the preference for sharing responsibility for decisions with a companion.

(13) *You and your daughter share responsibility?*

We usually do. I value her.

(22) I want them to [share in decision-making]. Because they've got brains, I mean, and education, and a lot of things.

(33) If they want to share it, then I would say that they could be in it. Yes. But don't think, if they'd say yes or no... I don't know. If they say no, I don't know.

Or do you think you would make the decision after seriously considering…

This one says we'd have three votes, yes?

This one says that you and your children would share equally. This one says you would make the decision after seriously considering their opinions.

I think we'd share it.

In explaining the role of her daughter, a participant who wanted her daughter to exercise the most control in decisions said, "My daughter makes them [health care decisions], and I agree with them." Another responded to the question about her children's role in future decisions:

(36) I think I would let them make the decision.

Is that what you want? Or is that what happened in the past.

Well I'm old... if it happened it happened. I didn't want to leave any bad feelings with them when I go. [Pause]

So it's better to go along with it than to ...

Fight it. They might know better than I know.

Control Preference: Physician Compared to Companion

Past Encounter

Ten of 20 participants who responded to questions concerning a past decision-making encounter involving the physician (1A) and companion (1B) selected the same CPS options to describe their preferred role for the physician and decision companion. Nine participants wanted the physician to have more control than the companion, in contrast to only one participant who wanted the companion to have more control than the physician. A Wilcoxon test was conducted to evaluate differences between involvement levels of the physician and companion in past encounters. The results indicated a significant difference that suggested more involvement in the past from the physician than from a companion, $z = -2.511$, $p = 0.012$. The mean of the ranks describing a greater

physician role was 5.72, while the mean of the ranks describing a greater companion role was 3.5.

Future Decision-Making Encounters

Half of 34 participants who responded to the two MCPS questions concerning the preferred role for the physician (2A) and the companion (2B) in future decisions preferred the same level of control for the physician and companion. Fifteen of the 17 participants who wanted different roles for the physician and companion in future encounters preferred a more involved role for the physician; only two preferred a more involved role for the companion. A Wilcoxon test indicated a significant difference between preferences in favor of greater control by the physician than the companion (z = -3.139, p = 0.002). The mean of the ranks reflecting a preference for physician involvement was 9.33 while the mean of the ranks reflecting a preference for companion involvement was 6.5.

Weight of Input from Physician and Companion
in Future Decisions

When asked to describe how they would weigh the physician's input against the companion's input in future decisions ***involving the participant***, 16 of 29 participants weighed the input equally. Eleven participants weighed the physician's input more than the companion's, with two weighing the companion's input more than the physician's, as shown in Table 6.7. A shift occurred, however, when participants were asked to consider a decision being made at a

future time when they were fully unable to participate in the decision-making process. Under that scenario, 20 of 29 participants weighed the input equally, with five weighing the physician's input over the companion, and four weighing the companion's input over the physicians. A Wilcoxon test showed that the shift toward the companion and away from the physician was significant, z = -2.828, p = .005. The mean rank representing shifts by eight participants toward greater companion input was 4.5, with a mean rank of 0 representing no shifts toward greater physician input.

Consistent with CPS responses, analysis of participant narrative responses also showed qualitative differences between how participants viewed the roles of physicians and their companions. The first observation was that physicians were viewed as experts.

> (02) *When you hear "doctor's opinion" in that question, what kinds of things should doctor put into forming his opinions?*
>
> He knows more than I know about it. So, I want his intake, but I still make up my own mind.
>
> (14) I relied on those guys. Those guys have had years and years and years and years of experience. You ask them a question, you should get a reasonable answer.
>
> (29) I just assume that the doctor knows what the hell he's talking about.

In contrast, family members who were not medical professionals were viewed as sounding boards or backstops. One participant with a diagnosis of vascular dementia described his son's role as follows:

(20) So we would have a discussion, but, at the same time, [Son] could say, "But Dad, we went through that, and we talked about what would happen if they did find something like that. It's my understanding that you would rather have me make that decision." And I said, I would say, "Yes, you're right." Because what I'm not sure of today. I'm not sure if somebody hasn't told me something that would change. So I could be manipulated, as it were. So this way, I've got a safety valve with [Son] saying "Dad, this doesn't make any sense, where you're going with this. And this is why." And then we'd go over it again... And right that minute, I'd say, "I understand what you're saying, and yes, I think we should go ahead with it then."

Another participant described her relationship with her family as follows:

(27) I always talk to them. After I talk to the doctor, I call my kids and I talk to them.

Would you say that you and your kids together decide?

I want their input just in case there's something that I haven't thought about.

Decision-Making Characteristics not Captured by the MCPS

Narrative text revealed characteristics about how participants viewed the decision-making process that was not fully captured by the MCPS.

Being Known by the Physician or Companion

In addition to relying on physician's expertise, many participants relied on the knowledge that both physicians and companions had about them personally.

(8) *Are there things the doctor should know about you when forming decisions about your care?*

No. I think he more or less knows.

....Do you want your doctor to understand your religious views, or is that not an issue for you?

He does. He may not have the same religion that I do, but he thinks about my religion.

(25) We've been with her [the family physician] so long. She knows my history and ... there's not anything I don't think she doesn't know.

Other participants emphasized that their companions, usually family members, knew them.

(9) [Daughter]'s pretty smart. Plus she knows me.

(10) [Step son] knows my religious values. Even though he himself is kind of an agnostic, he knows about my conservative Christian values and I think he would make decisions for me based on what he knows about me.

(18) You know, I would consider [wife's and daughter's] opinions. Because they know the history of you.

Participant in Control

None of the participants' responses suggested that they doubted their authority to be the decision-maker, even when they selected a passive role or

deferred decision-making to another person.

Past Level of Control not Aligned with Preferred Level of Control

Consistent with MCPS responses, participants described misalignment between the level of control exercised in past decisions and preferred level of control wanted in future decisions for some participants. Those who experienced misalignment typically wanted more control in future encounters than they exercised in the target encounter.

(1) I feel like I'm kind of out there alone anymore not really making decisions on my part alone. Everything I do is not my decision, fully. I think everybody else is trying to make the decision one way and I'm trying to live another way. So the decision don't seem to be mine completely.

(5) *So in some ways what you think happens is that it's your doctor and your daughter and [staff] who are making…*

Absolutely.

…the decisions and that

Yes.

…maybe this needs a picture that represents the doctor and the family, and you're not in the picture at all?

Um, just so you know how I understand that chart, from my viewpoint. My voice should be the voice, with support, is how I feel.

(9) [Physician] don't even seem to want to know me now. I think I've seen her twice, and she just kind of, it's her way or the highway.

That's not an approach that you want?

> Not from a doctor. I want them to talk to you and explain things, and say we're going to run these tests, I agree, fine, run the test and see if I do need [medications], but don't take me off of them.

Cognitive Status

Many participants made statements affirming their cognitive abilities, although no questions were asked to elicit that information.

> (3) [Daughter] thinks I have all this dementia. She doesn't know that I understand, and I can answer your questions and write letters if you need, but she thinks that she knows it all.
>
> (5) I don't feel that I'm too mentally handicapped so that I can't participate in my own decisions.
>
> (9) I'm not gone yet…. I want to know what's going on. It's my body and I may be wacky, but I don't think so.
>
> (10) I'm one of the more high functioning individuals.
>
> (13) Right now I'm capable of making the decisions and [son] doesn't have to.
>
> (20) I'm cognitive, I think, as we speak.
>
> (23) I would discuss it with [Son] but the final decision would be mine, as I said, as long as I'm compos mentis.
>
> (29) I'm not senile.
>
> (30) As long as I have my mental facilities, I want to make my own decisions.
>
> (31) I hope I have some brains left.

Participants did, however, acknowledge cognitive challenges, including some of the same participants who remarked on their cognitive abilities.

> (8) I was married to my husband. His last name is [removed]. This is awful but I can't quite remember his first name right now.
>
> (12) I didn't remember my last name when I was signing two get well cards. Everybody put their names down. I said my name was [first name], but I couldn't remember my last name! When the aide came in and told me, I said "That doesn't sound right." But I put it on anyhow.
>
> (20) I'm not sure if somebody hasn't told me something that would change. So I could be manipulated, as it were.
>
> (28) It just seems like lately, lately meaning end of the year. Things have just been coming at me. Enough to keep me confused.

End-of-Life Decision-Making

Although the script and probing questions did not seek to elicit end-of-life care preferences, more than half of the participants raised the issue.

> (17) I've got a living will. It says, if I have a problem, just comfort, that's all.
>
> (23) My goals. It's a day-by-day process. I never expected to live to be [age deleted], nor did I particularly want to, so I don't have any goals, per se, other than... There's a difference. I'm not tired of life, but I'm life tired. In an environment like this, we jokingly refer to ourselves as inmates, but, you know... It's one of these things where, if the switch were pulled tomorrow, or today, I would not be unhappy.

(27) I hope that when I pass on that I do it peacefully, and not be in pain.

(36) I just take what comes to me day by day. If I'm going to die, I'm going to die. I'll try to have everything in order so I ....

Congregate Living

Living in a congregate setting appears to be a challenge to decision-making. The single most common source of conflict and disagreement articulated by participants involved the decision about where he or she would live. One participant whose MoCA score was in the normal range described the decision to move into an assisted living facility.

(2) When I came here, it was my son's last word. Not mine. Not the doctor's, even though the doctor suggested it.... And so, my son made all the decisions for me to come here. Because the doctor said "NAME you cannot stay home." And I said " Why?" ... And [Son] made the decision. When I came in, everything was set up. And I cried for three days.

She went on to explain one aspect of living in the facility that bothered her.

I think I'm going to put up a sign: Please don't sit on my bed. It's the first thing they go to, my bed.

Another person described an involuntary move into an assisted living facility.

(5) I didn't like them moving me down here, in the guise of a visit with my granddaughter. I brought four outfits. And I didn't have any choice. So I didn't like that. I was very angry actually.... It was that I was going to come to visit my granddaughter. She wanted me to visit.... But oh my gosh, when they sold my car and cleared out my apartment, it just ... it

made me a very bitter angry person for a while. And then I decided that I can't hate my kids. They've got to be out here and I've got to love them in here. Thank the Lord I could. I still am wary about decision-making.

One participant referred to the status of living in assisted living as being "an inmate." Another used the terms "condemned" and "railroaded" when describing his admission to a nursing home. During the interview he said, "Of course I don't begrudge them, but it's because of my family that I've ended up in places like this." He explained his dislike of the setting, "It's not that there's anything wrong, it's just that I can't get out and get away…. Here, you don't move. Is it ok if I breathe?" When naming the facility at the end of the orientation section of the MoCA, he added "Prison" after the facility name. The same participant refused to answer MCPS question 2B, which asked how he wanted his children involved in future decisions.

In discussing the relationship with the physician, several nursing home residents remarked that decision-making was adversely affected by their limited access to a physician.

(14) You know what? You rarely see a doctor here…. I don't know how long it's been since I've seen a doctor. Dr. [Name omitted]. He's a good guy. I probably haven't seen [him] for a month. I hear that he's been here, but I don't see him. I just don't see him. And then I'll see him maybe five minutes? At the most.

(30) They change your meds. They remove something or add something, and it's not up for discussion. You don't even see the doctor here. Unless you're dying, I guess. I haven't pulled that one off yet. [Laughter]. You feel

like you're not being involved. I'd like to be involved more. And I can understand why I'm not. I don't go around begging to be involved. I'd prefer it if they would give me a little piece of paper saying what's going on. I would relish that…. He comes along, he sees me in the hall. He puts his stethoscope here, 1, 2, 3, and he's gone. And he's done his check-up for the year or whatever it is.

Relationships Between MoCA Subscales and Scaled Score and MCPS Choices

Using Spearman's Rho, the relationships among MoCA subscale scores and MCPS choices were explored. After applying the Bonferroni correction to control for multiple tests, the only significant relationships ($p < .05$) were between the visual/spatial subscale and MCPS 1B (companion/past decision) (-.780, df=13, p=.028).

Fatigue with the Interview

The investigator who conducted the interviews as well as the investigator who coded the transcripts observed that fatigue was apparent in some participants' responses as the interviews progressed. Participants were offered the opportunity to stop the interview if the interviewer perceived emotional or physical discomfort. Although all completed the interview portion of the study, three declined to take the MoCA. Mean interview length from the time consent was obtained to the end of the MoCA test was 41 minutes (SD ± 17).

Discussion

This study asked participants the same question from six different perspectives with semistructured cognitive interviewing questions interspersed. That approach helped to provide a nuanced and rounded description of participants' preferences for decision-making involvement. The approach also helped to identify some aspects of the decision-making process that are not captured by the MCPS.

Study Procedures

The MCPS was effective at eliciting the decision-making preferences of participants across a range of cognitive function. The cognitive interviewing questions added depth to the understanding of the participants' perspectives.

The most problematic procedures involved attempts to elicit a past encounter. This was evidenced by the difference between the number of participants who provided responses to the backward-looking MCPS questions were fewer than those who responded to the forward-looking MCPS questions: 29 compared to 35 for the physician-related questions, and 25 compared to 36 for the companion-related questions (Table 6.6). The use of the SDS relied on identifying the target encounter. While the SDS might be effective in evaluating a recent encounter, it had a ceiling effect when used in the manner it was used in this study. To evaluate the use of the SDS in this population, future studies could evaluate the decision-making process immediately after the encounter.

Another important but unsuccessful part of this study was the failure to recruit the decision companions. Similar studies have required that the

companion consent before either member of the dyad is enrolled (Karen B. Hirschman, Xie, Feudtner, & Karlawish, 2004; J. H. T. Karlawish et al., 2002). That approach may cause selection bias and rule out involvement of individuals who lack a caregiver or who do not want to participate as part of a dyad.

In contrast, this study is limited by having only the perspective of the older adult. Past studies suggest that the older adult and companion may not have views that are aligned (K. B. Hirschman, Joyce, James, Xie, Casarett, et al., 2005; K. B. Hirschman, Joyce, James, Xie, & Karlawish, 2005). If policy and practice continue to move toward an inclusive approach to decision-making, it will be important to understand how dyads work, and how to support both the older adult and companion working within a supported decision-making model.

Decision-Making Preferences

Participants across a range of cognitive function assumed that they were the decision-makers, and all expressed a preference to be involved in decisions about their care to some degree. These findings are consistent with the results of one study that addressed a similar research question (K. B. Hirschman, Joyce, James, Xie, Casarett et al., 2005; K. B. Hirschman, Joyce, James, Xie, & Karlawish, 2005). Most participants also described different roles for physicians and family members, with physicians typically characterized as experts, and family members serving a reflective and deliberative role in the process. Many participants assigned a more substantial decision-making role to the physician than to the family. Contrasting the typical view of decision-making for older adults as occurring in a triad (Kapp, 1991; Wolff & Roter, 2008), participants

appeared to view decision-making as between two dyads. However the question structure, which posed each series of questions as two dyads, could have influenced how the responses were framed by participants. If, on the other hand, older adults across a range of cognitive function do view decision-making as occurring within two dyads, not a triad, it would have implications for both clinical practice and policy. Further exploration of this observation is therefore warranted.

A minority of participants had conflict in the decision-making process with physicians who were viewed as too directive, or where past treatments had bad outcomes. A minority of participants also had conflicts with families over decision-making, with most conflicts arising in the decision to place the participant in an assisted living facility or nursing home. In contrast, many participants described positive support they received from family and physicians. A future study could investigate how to minimize conflict in these relationships.

Self-Perception of Cognitive Status

Many participants remarked on their own cognitive status, typically asserting that they retained the ability to participate in decisions. A few participants were sensitive to the sense that others were not showing respect for them. Others provided descriptions of providers and families who continued to honor them in the face of cognitive decline. This is an area that has not been explored, but that warrants further study.

Study Limitations

The study's small sample size was its most substantial limitation. The study population was not necessarily representative of all older adults, because it was not ethnically diverse, it represented only facility-dwelling individuals, and it was a highly educated group of people. The study sample could also be affected by selection bias, because about one-third of those who were invited declined to participate. In addition, participants were referred by facility employees who had the ability to exclude individuals for reasons other than their failure to meet inclusion criteria.

Future Studies

Although most of the participants in this study preferred autonomous decision-making when considering the role of a decision companion, many would need support in decision-making that the companion would provide. Future studies should consider how to help individuals and their companions to navigate the complicated world of medical decision-making in the even more complicated context of limited available options, limited resources, and complex relationships.

Future studies should also develop ways to meaningfully engage individuals with impaired decisional abilities in decisions about their care. Although participants leaned heavily toward engaging with the physician, those physicians often lack the skills, training, and time to meaningfully engage in a decision-making process with individuals with impaired decisional abilities.

Intervention studies could examine different strategies for meaningful engagement.

The finding that all participants viewed themselves as responsible for their decisions raises questions about the recommendations described in the introduction that instruct providers to obtain consent from a surrogate once the patient has been found to have capacity that falls below a certain threshold. Although this study was not designed to assess capacity, it is likely that many of the participants, perhaps even a majority, would have been found to lack the capacity to make their own treatment decisions under current assessment instruments, such as the MacArthur Capacity Assessment Test-Treatment. Additional research is needed to understand how consent is obtained when providers question their patients' ability to provide informed consent. In cases where the patient is excluded from decision-making, it is important to develop an understanding about what impact exclusion has on the individual's emotional and physical wellbeing.

Conclusion

The words of one participant summarize the findings of this study: "I know they have restrictions and rules they have to follow. I know that. But listen to me. *Listen to me*. And that's how I feel."

Table 6.1

CPS Question Series and Response Options

1A: Thinking about [the target visit], can you describe how you participated in the decisions that were made?				
A	B	C	D	E
Active		*Collaborative*	*Passive*	
I made the decision about which tests or treatments I received.	I made the decision about which tests or treatments I received after seriously considering my doctor's opinion.	My doctor and I shared responsibility for deciding which tests or treatments I received.	My doctor made the final decision about which tests or treatments I received after seriously considering my opinion.	My doctor made the decisions about which tests or treatments I received.
1B: Think about that visit, but instead of thinking about the doctor's role, think about the role of [COMPANION] who was there with you. Can you select the option that best reflects how you made the decision?				
A	B	C	D	E
Active		*Collaborative*	*Passive*	
I made the decision about which tests or treatments I received.	I made the decision about which tests or treatments I received after seriously considering [NAME]'s opinion.	[NAME] and I shared responsibility for deciding which tests or treatments I received.	[NAME] made the final decision about which tests or treatments I received after seriously considering my opinion.	[NAME] made the decisions about which tests or treatments I received.
2A: Think about a doctor's visit where a decision is made in exactly the way you want. Can you tell me how you want your doctor involved?				
A	B	C	D	E
Active		*Collaborative*	*Passive*	
I prefer to make the decisions about which tests or treatments I receive.	I prefer to make the decisions about which tests or treatments I receive after seriously considering my doctor's opinion.	I prefer that my doctor and I share responsibility for deciding which tests or treatments I receive.	I prefer that my doctor make the final decisions about which tests or treatments I receive after seriously considering my opinion.	I prefer to leave all decisions about which tests or treatments I receive to my doctor.
2B: Think about a doctor's visit where a decision is made in exactly the way you want. Tell how you want [DECISION COMPANION] to be involved				
A	B	C	D	E
Active		*Collaborative*	*Passive*	
I prefer to make the decisions about which tests or treatments I receive	I prefer to make the final decisions about which tests or treatments I receive after seriously considering [NAME]'s opinion.	I prefer that [NAME] and I share responsibility for deciding which tests or treatments I receive.	I prefer that [NAME] make the final decision about which tests or treatments I receive after seriously considering my opinion.	I prefer to leave all decisions about which tests or treatments I receive to [NAME].
3A: When making decisions about your treatment right now, how do you weigh the input of your doctor and the input of [DECISION COMPANION]?				
A		B		C
My doctor's input weighs most heavily.		[NAME]'s input weighs most heavily.		My doctor's input and [NAME]'s input are about equally important.
3B: If you were unconscious and seriously ill, how would you weigh the input of your doctor and the input of [NAME]?				
A		B		C
My doctor's input weighs most heavily.		[NAME]'s input weighs most heavily.		My doctor's input and [NAME]'s input are about equally important.

Table 6.2

Demographic Information of Subjects (N=37)

Characteristic	*N* (%)
Age, years (mean ± *SD*)	81.8 ± 9.3
Female, *n* (%)	25 (68%)
Race, *n* (%)	
Hispanic	1 (2.7%)
African American	1 (2.7%)
Asian	1 (2.7%)
White	34 (91.9%)
Marital status, *n* (%)	
Single	5 (13.5%)
Divorced	9 (24.3%)
Married	5 (13.5%)
Widowed	18 (48.6%)
Education, *n* (%)	
≤ High school graduate	10 (27%)
Some college	15 (40.5%)
≥ College graduate	12 (32.4%)

Table 6.3

Participant's Relationship with Decision Companion

Primary Decision Companion		Secondary Decision Companion	
Spouse	5 (14%)	Child/Children	4
		Nephew	1
Child/Children	27 (75%)	Facility Staff	2
		Sibling	1
Sibling	1 (3%)		
Friend	2 (6%)		
Facility Staff	1 (3%)		

Table 6.4

MoCA Scores

	Scaled	Raw	High
Mean ± *SD*	19.1± 4.9	17.7 ± 5.5	19.74 ± 4.3
Range	7, 29	7, 29	7,29
≥ 26* (no impairment detected)	3, 9%	2, 6%	3, 9%
18-25* (mild cognitive impairment)	19, 56%	16, 47%	20, 59%
< 17* (moderate to severe impairment)	12, 35%	16, 47%	11, 32%

(Nasreddine, 2014)

Table 6.5

Satisfaction with Decision Scale Responses

	Agree	Disagree	Total
Adequately informed	26	6	32
Best decision for me personally	27	3	30
Consistent with personal values	27	2	29
Successfully carry out	30	1	31
My decision to make	24	6	30
Satisfied with decision	29	3	32

Table 6.6

Participant's Decision-Making Involvement Preferences

		A	B	C	D	E	Total
Past	Physician	1	9	9	5	5	29
	Companion	4	8	9	2	2	25
Future	Physician	1	12	18	4	0	35
	Companion	8	16	9	2	1	36

A. I make the decision…

B. I make the decision … after seriously considering [name or role]'s opinion

C. [Name or role] and I shared responsibility…

D. [Name or role] makes the decision … after seriously considering my opinion

E. [Name or role] makes the decision…

Table 6.7

Participant's Relative Weight of Importance of Physician vs. Companion

	Physician > Companion	Physician = Companion	Companion > Physician	Total
Participant Involved in Decision	11	16	2	29
Participant Unable to Participate	5	20	4	29

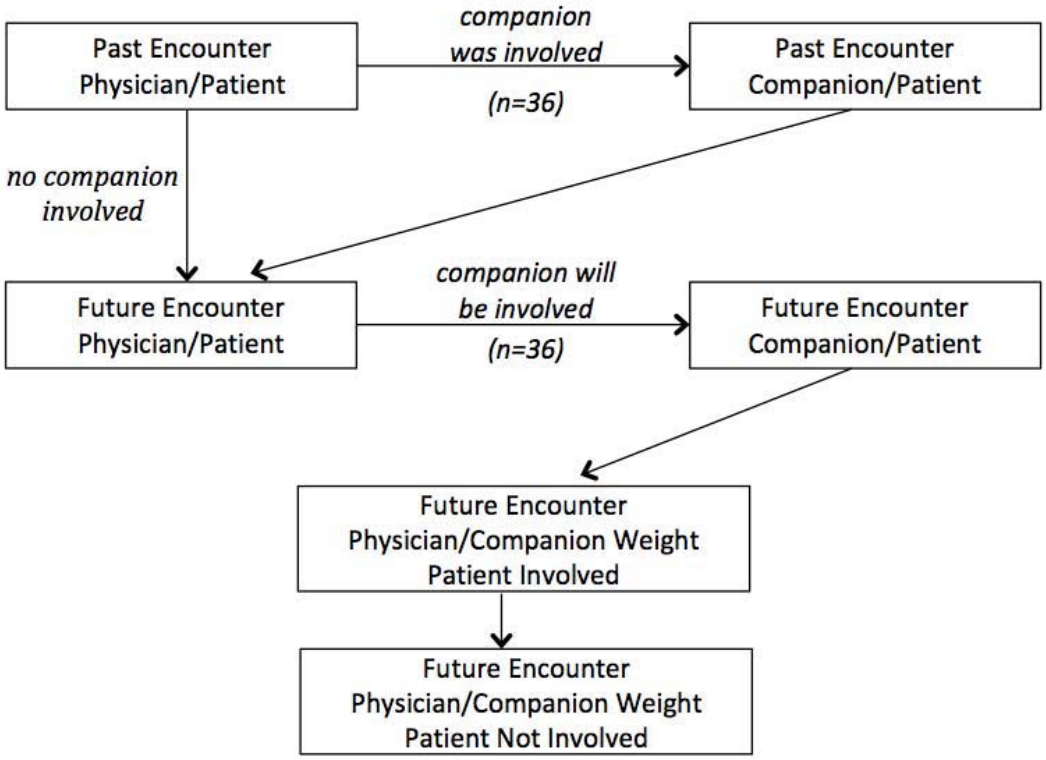

Figure 6.1. Flow of Modified CPS Question Series

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CHAPTER 7

CONCLUSION

This study has explored the ethical, legal and policy aspects of decision-making involvement for older adults across a range of cognitive function. There were three purposes for the study. The first was to understand the origins of the legal standards paradigm for capacity assessment and evaluate whether the approach remains an appropriate way to address the decision-making needs of older adults with impaired decisional abilities. The second was to evaluate whether the CPS and NQ are reliable and valid instruments for eliciting the decision involvement preferences of older adults across a range of cognitive function. The third was to generate a description of the decision involvement preferences of older adults across a range of cognitive function.

The study makes the assertion that supported decision-making with older, facility-dwelling, adults, even those with impaired decisional abilities, is ethically sound and highly desirable, and provides evidence that using the Control Preference Scale to elicit involvement preferences that can serve as the basis for supported decision-making is reliable and feasible.

Major findings and the relationships between those findings are discussed in this chapter. The chapter also contains recommendations for the future of decision-making for older adults with impaired decisional abilities.

Ethics, Law, and Policy Addressing the Needs of Older Adults with Impaired Decisional Abilities

The history and theory review of the legal standards paradigm for decision-making capacity was undertaken to explore why the legal standards paradigm was built on a dichotomous view of capacity, and whether the exclusion of individuals from decisions about their care is justified by empirical evidence or ethical principles. The inquiry identified a number of concerns. The paradigm relies on untested assumptions about ethical behavior, the relationship between law and ethics, and the superiority of surrogate decision-makers over individuals whom clinicians have judged to lack capacity.

First, the paradigm rests on the assumption that it is possible to categorize all individuals into a dichotomous framework, although everyone who addresses the issue agrees that capacity is on a spectrum. Within the dichotomous framework wherein individuals found to "have capacity" are viewed as being fully autonomous and capable of making treatment decisions without assistance, and individuals found to "lack capacity" are viewed as fully lacking the ability to exercise autonomy, so they must be replaced by surrogates in the decision-making process (Berg et al., 1996). Building on concerns articulated by Kapp and Mossman (1996) nearly 2 decades ago, my analysis in Chapter 4 suggests that concerns about the legal standards paradigm have not been addressed by

researchers or ethicists in either the theoretical or clinical context. One concern is the error rates reported for every instrument developed to categorize individuals in a dichotomous structure (Moye, Marson, & Edelstein, 2013) that could be considered too high for such a high-stakes evaluation.

A second assumption is that excluding patients whom a provider has found to lack capacity from decisions about their care is consistent with the ethical principle of beneficence. This broad assumption rests on two further assumptions.

The legal standards paradigm assumes that taking away an individual's right to make decisions causes less harm than allowing n individual deemed to "lack capacity" to make decisions. Empirical studies evaluating the Stress Process Model (Menne, Johnson, & Whitlatch, 2008; Menne, Judge & Whitlatch, 2009; Menne, Tucke, Whitlatch, & Feinberg, 2008; Menne & Whitlatch, 2007; Whitlatch & Menne, 2009) and Self-Determination Theory (Kasser & Ryan, 1999) provide evidence that removing individuals from decisions about their treatment, just as removing them from decisions about daily life, could cause harm. This evidence, albeit indirect, is not counterbalanced by any evidence that a system that categorically removes every individual from treatment decisions once a provider finds that the individual lacks capacity under a dichotomous framework is grounded in beneficence. There is no empirical evidence that the application of the legal standards paradigm strikes the right ethical balance between beneficence and autonomy.

An alternative to the legal standards paradigm is to shift the research focus away from dichotomous classification of older adults into those who have and

those who lack capacity and instead use existing research on capacity to identify both strengths and weaknesses in patients with impaired decisional abilities. An emerging approach is supported decision-making, which has been implemented in Canada, and was recently recognized in a decision issued by a Virginia court.

The evidence that increased inclusion and engagement improves the well-being of individuals supports the need to explore strategies that engage individuals, even those with impaired decisional abilities, in decisions about their care. Supported decision-making is one such strategy. Empirical evidence and quality metrics will be necessary to assure that supported decision-making structures provides needed and appropriate support. There is a risk that supported decision-making could become surrogate decision-making in disguise.

The conclusions described in Chapter 4, particularly when combined with the evidence reported in Chapter 6 that all of the study participants saw a role in decision-making for themselves, support a re-evaluation of the advice that individuals found to "lack capacity" should be removed from decisions about their care and replaced by surrogate decision-makers. Without any change in law, providers can immediately begin to use shared decision-making techniques. For example, they can use the Control Preference Scale (CPS) to elicit patient preferences for involvement in decision-making. This need not be limited to patients suspected of having impaired decisional abilities: As noted by Nolan et al. (2005), the decision-making preferences of patients without suspected decisional abilities are heterogeneous and are often misunderstood. Additional recommendations for research and policy are made below.

Reliability and Validity of the MCPS in the Study Population

The research study addressing Aims 2 and 3 was designed to evaluate the use of the MCPS among older adults representing a range of cognitive function. There is a dearth of research that asks older adults with impaired cognitive function about their preferences (Beard, 2004); rather, in most studies individuals with impaired cognitive function are excluded from participation (Taylor, DeMers, Vig, & Borson, 2012). As reported in Chapter 5, this study provides preliminary evidence that the MCPS was reliable and valid when used to elicit the decision involvement preferences of participants in this study.

Modified Control Preference Scale

Although the CPS has been widely used to assess decision involvement preferences in other populations, including older adults, the author has not found any use in adults suspected of having impaired cognitive function. The study found no evidence to suggest that participants were unable to use the MCPS to describe their involvement in past encounters in relationship to both the physician and a companion, and to describe their preferred involvement in future encounters. The study provided evidence that participants' choices on the MCPS reflected their preferences.

By including two items asked of participants in the study by Nolan et al. (2005), it was possible to identify similarities and differences between participant responses over more questions. It was also possible to test the internal consistency and logic of participant's responses by asking a question that was very similar to a pair of MCPS questions.

The preferences of participants in this study were strikingly similar to the preferences of participants in the Nolan study (2005). Although it was expected that the profile of responses might have similarities, the level of similarity was unexpected because the two study populations had very different demographic characteristics, with a significant difference in mean age (62 versus 82). In addition, participants in the Nolan study were selected because they had recently been diagnosed with an illness that had a life expectancy of approximately 2 years. Despite these differences the responses were similar.

The similarities suggest the construct validity of using the MCPS in older adults with cognitive impairment. "[C]onstruct validation is an ever-extending process of investigation and development" (Peter, 1981, p. 135). The correlations between responses offered by participants in this study and the Nolan study are evidence to support the validity of using the MCPS in the study population.

Correlations Among Responses to Different Items Representing the Same Construct

Response patterns among three related items (MCPS 2A and 2B, which comprise the relative control score, and MCPS 3A) were analyzed to determine whether the responses that provided relative weight of involvement by the physician and companion were correlated. A relative control score was compared to the NQ input weight question. Although 71% (20/28) of the paired relative control score and MCPS 3A selection were matched, the results were not significant, likely due in part to the small sample size with limited power.

Perhaps as important as the correlations is the qualitative evidence that this item provides, suggesting the presence of logic within the participants' responses. The 20 matched pairs were fully in line with rules of deductive logic because the response patterns were the same (e.g., relative control score "physician > companion" is logically aligned with MCPS 3A input weight "physician > companion." Pairs with opposite patterns defy the rules of deductive logic (e.g., relative control score "physician > companion" is incompatible with MCPS 3A input weight "physician < companion"). Only two of the 28 participants responded in this manner. The other six patterns are inconclusive as to logic because the imprecision of language does not allow a comparison.

Internal Consistency Among MCPS Items

Another way to evaluate the reliability of a scale is to calculate a Cronbach's alpha. In this study, the four MCPS items 1A, 1B, 2A, and 2B had an acceptable level of internal consistency, as determined by a Cronbach's alpha of 0.764. This result not only serves as evidence that the four MCPS items are measuring the same construct, it also suggests that responses are reliably capturing a single construct across the study population.

Analysis of Narrative Responses

Overwhelmingly, responses to semistructured interview questions and spontaneous explanations offered by participants throughout the interview supported the reliability and validity of the participants' responses to the MCPS

items. There was a corresponding lack of evidence of that responses were not reliable or valid.

Although a few participants struggled with the instrument, most easily selected among options offered and affirmed that the MCPS accurately captured their views of the relationships within the decision-making process. These findings support the use of the MCPS in clinical practice and in future research studies.

A limitation of the study is that the inclusion criteria prevented the identification of individuals with a level of impairment where the MCPS would not effectively capture preferences. Further research would be necessary to determine where that point is.

Significance

The results of this portion of the study are important because they support the validity of an easy-to-use instrument that could be used in research and clinical settings to describe past encounters and preferences for involvement in future encounters by older adults across a range of decisional abilities. Those who were able to respond to the MCPS included participants with MoCA scores as low as 7 and 10, suggesting severe impairment. As providers are increasingly asked to deliver care that is patient-centered, whether in the context of shared or supported decision-making, instruments such as the MCPS will be important tools for eliciting the involvement preferences of patients across a range of cognitive function.

Limitations

There are older adults with decisional abilities (or, in some cases, functional abilities, such as the ability to communicate) who would be unable to respond to the MCPS or whose responses would not meaningfully connect their preferences to their choice of MCPS options. This study did not identify any such individuals, in part, because participation in the study was cognitively demanding. Some potential participants were excluded because they lacked the physical or cognitive endurance needed to participate, or because they lacked understanding of their role in a research study. Although one participant scored in a range suggesting severe cognitive impairment and many scored in a range suggesting moderate impairment, the study did not identify the level of impairment where individuals would be unable to express choices about care through the MCPS. To address this limitation, future studies could separate the question series into more than one interview to reduce its demands on participants.

Another limitation was the portion of the study that asked participants to identify and remain focused on a target encounter. Some participants had difficulty identifying a target encounter, as evidenced by number of responses received: 25 participants responded to the MCPS items reflecting past encounters compared to 35 participants who responded to MCPS items reflecting future preferences. Other participants may have been distracted by the preliminary emphasis on the target encounter; some participants continued to focus on the target encounter even when asked about their preferences for future encounters. Discussions eliciting and evaluating the target encounter did,

however, generate rich text that contributed to an understanding of how study participants viewed their roles in the decision-making process.

A second limitation concerning the recall of a past encounter involves the limits of memory (Kahneman & Riis, 2005; Shell, 2013), wherein past memories are filtered through experience. Typically, current expressions, such as participants' responses to the MCPS that describe current preferences for decision involvement, will be more accurate than recollections of past perceptions. This challenge is not unique to this study; it affects every study where participants are asked about past events. In the context of this portion of the study, the accuracy of participants' descriptions of past encounters was less important than their narrative descriptions, which provided a basis for comparing and evaluating their MCPS responses.

Satisfaction with Decision Scale (SDS)

The portion of the study that asked participants to identify a target encounter, and to rate that encounter using the SDS, was far less productive than the sections evaluating the MCPS. The large majority of participants responded "agree" to most of the questions, including participants who subsequently expressed dissatisfaction with the encounter. The lack of success with the SDS in this context does not suggest that the instrument would not be helpful in eliciting real-time evaluations of decision-making encounters. It has been used in at least one study involving older adults with impaired cognitive function (Carmody et al., 2014), and its use in this population could be further evaluated in future studies.

Preferences for Decision-Making Involvement

This study is the first that the author is aware of that provides evidence that older adults across a range of cognitive function (MoCA Range 7-29) overwhelmingly want to be involved in their treatment decisions. A related but unanticipated finding that emerged was that all participants (even the few who selected a passive role) viewed themselves as being in control of the decision-making process. A third, also unanticipated finding was that many participants viewed their relationships with the physician and companion as two dyads, not a triad.

Overwhelmingly, participants expressed a preference for involvement in care decisions. Specific distribution of participant CPS responses with related narrative text was explored in Chapter 6. This author has observed that providers sometimes assume that older adults' preferences are either independent or passive in the extreme; the study findings suggest that those assumptions are not true.

The view that older adults on average prefer more passive roles in decision-making than younger patients has received some support from studies using the Control Preference Scale to evaluate older adults' preferences. For example, a study by Rodriguez et al. (2008) found that older participants leaned toward more passive roles. The more assertive preferences selected by participants in this study aligned with the findings of Nolan et al. (2005), which, in contrast to Rodrigues and colleagues, used the CPS to compare participants' preferences for decision-making involvement with both the physician and a companion.

This study shows that preferences for involvement among participants with cognitive impairment, like preferences of patients facing serious, life-limiting illness in the study by Nolan et al. (2005), are heterogeneous, although some patterns emerge. For example, there was a shift to more weight on the companion's role in decision-making after the participant cannot participate in decision-making. "Discerning the composite weight each patient would give to his or her own preferences, his or her loved ones' input, and physician input is a complex process" (Nolan et al., 2005). This study echoes that conclusion: understanding the decision-making preferences of older adults across a range of decisional abilities is a complex process.

In addition to the qualitative data describing participants' MCPS choices, two unanticipated codes emerged from the text. The first was that all participants spoke in a manner that suggested that they were the primary decision-maker. Although some expressed distress when they felt disrespect or neglect from others in the decision-making process, they did not express doubt that they remained the deciders. Even those participants with the lowest MoCA scores were articulate in expressing past and desired future roles in care. Many participants referenced their own cognitive status in responses, stating that at the time of the interview they were able to make their own decisions.

The second unanticipated finding was that most participants characterized decision-making as occurring within two dyads (patient/physician and patient/companion(s)), not as a triad. This finding is inconsistent with the common view that decision-making for geriatric patients functions as a triad (Greene & Adelman, 2013; Kapp, 1991). This view may arise from the practical

fact that family or other companions often accompany older patients to medical appointments. In reporting their results, Nolan and colleagues observed, “These findings partially support, but also partly undermine, claims that the family has a large role in making medical decisions for patients with capacity in the United States” (2005, p. 348). The same can be said for patients with impaired decisional abilities who would likely be found to lack capacity

Significance

The findings concerning participants’ preferences raise serious questions about the current approach to addressing medical decision-making by or on behalf of patients with impaired decisional abilities. Many of these participants would likely be judged to lack capacity to make a major healthcare decision, but all expressed a desire to participate in making decisions about their care. Excluding them from the decision-making process could certainly cause the distress articulated by the few participants who described instances where decisions were made that were contrary to their wishes. That said, many would need support in decision-making from either a companion or a provider.

Another aspect of the findings that raise concerns is the discrepancy between the substituted judgment model of surrogate decision-making and preferences for decision-making among the participants in this study, as well as the Nolan study. Even in the face of incapacity, many participants want their physicians to play a more significant role in the decision-making process than their companions, yet the approach to surrogate decision-making would, by default, place the companion over the physician in the decision-making

hierarchy. Research is needed to investigate whether the current models for surrogate decision-making reflect how individuals want decisions made and, if not, what better models might exist.

The dynamic seen in this study and Nolan study suggests a need to question assumptions about the family's role in decision-making, and to explore how to most effectively involve family in the decision-making process, whether or not the patient lacks capacity. Providers can explore patients' preferences about the role of the family in decision-making, and can work to accommodate those preferences to the extent possible.

Study Limitations

The study's small sample size was a substantial limitation. In addition, the study population was not necessarily representative of all older adults, because it was not racially or ethnically diverse, it represented only facility-dwelling individuals, and it was a highly educated group of people. The study sample could also reflect selection bias, because about one-third of those who were invited declined to participate. In addition, the individuals invited were referred by facility employees who could have excluded individuals for reasons other than their failure to meet inclusion criteria. Future studies could address these limitations.

Future Research Directions

A well developed approach to supported decision-making would address many of the concerns raised by this study's findings. In the clinical setting, right

now, providers can use existing tools to understand the role patients want in making decisions about their care in relationship with their providers and their companions (CPS) and the patients' abilities and areas in need of support. Instead of using capacity assessment instruments to make dichotomous judgments that result in the exclusion of individuals from decision-making, providers could use them to identify areas where they can offer support. Providers, even now, have a rarely mentioned a duty to try to ameliorate the effects of sensory disabilities, medical conditions, or behavioral health concerns to allow the person to most fully participate in decisions. Physicians should seek the support of nurses, social workers, psychologists, speech therapists, and other providers to assist in this process, when feasible.

If an individual remains unable to make decisions without support, providers can establish decision-making strategies, such as memory assistance or eliciting preferences that can help to make choices among options. Providers can adopt strategies that show basic respect for individuals with impaired cognitive function by including them in the decision-making process to the degree they desire. For example, when getting signatures on consent forms, both the individual and a companion can sign together. Providers could resort to exclusion only when other options, such as support from nursing and social work, have failed.

While there are work-arounds available to providers, more is needed. Research is needed to create and evaluate interventions to meaningfully engage people with impaired decisional abilities in decisions about their care. Although participants leaned toward engaging with the physician to make decisions, those

physicians may lack the skills, training, and time to meaningfully engage in a decision-making process with individuals with impaired decisional abilities.

Older adults with impaired cognitive function, as well as other populations of people who would benefit from supported decision-making, may be vulnerable to abuse or coercion. Strategies are needed to assure that decision-making processes are designed to elicit the person's preferences, and don't simply make it appear that the provider's or companion's preferences are the person's.

Future studies should also consider how to help individuals and their companions to navigate the complicated world of medical decision-making in the even more complicated context of limited available options, limited resources, and complex relationships.

Implications for Education

The study supports the need for education of all healthcare providers who participate in the process of obtaining informed consent, whether in a formal setting where a form is being signed, or in a less formal setting where routine care is being delivered. There is evidence that misunderstandings about capacity are rampant; if the rights of vulnerable patients are to be respected, capacity should be understood by all health care professionals.

Although most professionals would receive some training in ethics that touches on informed consent and capacity, if detailed, the training would be based on the legal standards approach to capacity assessment. The results of this study suggest that providers should receive training to look beyond the legal standards approach to the ethical principles and, for each individual, consider

whether exclusion from decision-making is necessary. Further training – not yet developed – could provide the skill in eliciting preferences and meaningfully engaging older adults in decisions about their care, even as they face impaired decisional abilities. Ideally, such training would be offered as continuing education for professionals and as part of degree preparation.

Conclusion

Work is needed to develop a new legal, clinical, and ethical framework for addressing the decision-making needs of older adults whose decisional abilities are impaired or in decline. Some of the work will be in the legal and policy arena, but human subjects research is also needed to develop a model of decision-making involvement, including supported decision-making for older adults with impaired decisional abilities. For many reasons, research on shared decision-making, specifically, and decision-making preferences, generally, has been conducted in populations of individuals without impaired cognitive capacity. The vast majority of research on individuals with impaired decisional capacity has focused primarily on instruments and measures designed to determine when the individual should be excluded from the process, not on how to understand the individual's desire to be included in the process, or when inclusion is the desire, how to include the individual in decisions about medical treatment. The absence of research on decision-making patterns and preferences among a population of older adults representing a range of cognitive function has left gaps in clinical best practices and informed consent theory and policy.

A model of inclusive decision-making for older adults with impaired decisional abilities will require the development of interventions and clinical best practices to promote the inclusion of individuals in decisions about their care. A program of research is needed to provide direction to policy-makers, as well as patients, caregivers, providers, attorneys, and judges who need guidance in addressing the decision-making needs of older adults with impaired decisional abilities. The results of this study will provide basic information that will serve as the building block for a new approach to decision-making for older adults with impaired decisional abilities. Hopefully, the results will also encourage providers to consider how to meaningfully engage all patients who want to be involved in their treatment decisions.

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APPENDIX

STUDY QUESTIONNAIRE

Record ID	
Age (in years)	
Gender	☐ **Male** ☐ **Female**
Race/Ethnicity	☐ **Non-Hispanic White** ☐ **African American** ☐ **Hispanic** ☐ **Native American** ☐ **Asian/Hawaiian Native/Pacific Islander**
Highest Education	☐ **Less than High School** ☐ **High School Graduate or Equivalent** **Some College** ☐ **College Graduate** ☐ **Post-Graduate**
Marital Status	☐ **Single** ☐ **Married** ☐ **Divorced** ☐ **Widowed** ☐ **Other**
City/Town of residence	
Setting	☐ **Home** ☐ **Assisted living** ☐ **Nursing home** ☐ **Other**

Decision Companion

Is there someone who goes to doctor's appointments with you and helps with appointments?	☐ Yes ☐ No
Does this person help you make decisions about medical tests or treatments?	☐ Yes ☐ No
Is this the same person you would want to make medical decisions for you if you were unconscious and seriously ill?	☐ Yes ☐ No
What is your relationship with that person?	☐ Spouse ☐ Child ☐ Sibling ☐ Parent ☐ Grandchild ☐ Other
What does the person do at your doctor's appointments?	☐ Writes down what doctor says, records instructions, takes notes, remembers ☐ Gives information, explains your medical condition or needs to the doctor ☐ Explains doctor's instructions to you ☐ Asks questions ☐ Translates language ☐ Schedules appointments ☐ Nothing ☐ Keeps me company, sits with me ☐ Moral support ☐ Transportation ☐ Physical assistance with walking or dressing Helps me to decide between tests and treatments being offered ☐ Other

TARGET ENCOUNTER: Think about a recent encounter with a doctor where decisions were made about whether you should have tests or treatments. Can you tell me a little about it? Where necessary, prompt:

- What kind of a doctor?
- What was happening that caused you to see a doctor?
- Did you receive any treatment or tests (prescriptions, x-rays, other) as a result of the doctor visit?

SATISFACTION WITH DECISION SCALE (SDS)

	Agree	Neutral	Disagree
I am satisfied that I was adequately informed about the issues important to my decision			
The decision I made was the best decision possible for me personally.			
I am satisfied that my decision was consistent with my personal values.			
I expect to successfully carry out (or continue to carry out) the decision I made.			
I am satisfied that this was my decision to make.			
I am satisfied with my decision			

Was there anything about the visit or your satisfaction that you would like to explain?

CONTROL PREFERENCE SCALE (CPS): PAST ENCOUNTER

Thinking about that visit, can you choose the option that best describes how you participated in the decisions that were made? (*show illustration*)

- ☐ I made the decisions about which tests or treatments I received.
- ☐ I made the final decisions about which tests or treatments I received after seriously considering my doctor's opinions.
- ☐ My doctor and I shared responsibility for deciding which tests or treatments I received.
- ☐ My doctor made the final decisions about which tests or treatments I received after seriously considering my opinions.
- ☐ My doctor made the decisions about which tests or treatments I received.

Cognitive Interviewing Probes:

- Was the way decisions were made offered as a choice in the previous question?
- Can you tell me about the decision in your own words?
- Can you explain why you chose the option you did?
- What kinds of things would you want your doctor to consider when forming opinions about the treatment you would receive?
    - Spirituality? Religion? Cost?
- Additional probing questions when necessary.

Think about that visit. Instead of thinking about the doctor's role, think about the role of [COMPANION] who was there with you. Can you select the option that best reflects how you made decisions.

- ☐ I made the decisions about which tests or treatments I received.
- ☐ I made the final decisions about which tests or treatments I received after seriously considering [COMPANION]'s opinions.
- ☐ [COMPANION] and I shared responsibility for deciding which tests or treatments I received.
- ☐ [COMPANION] made the final decisions about which tests or treatments I received after seriously considering my opinions.
- ☐ [COMPANION] made the decisions about which tests or treatments I received.

Cognitive Interviewing Probes:

- Was the way decisions were made offered as a choice in this question?
- Can you tell me about the decision in your own words?
- Can you explain why you chose the option you did?
- What kinds of things would you want your companion to consider when forming opinions about the treatment you would receive?
    - Spirituality? Religion? Cost?

Additional probing questions when necessary.

CONTROL PREFERENCE SCALE (CPS): FUTURE ENCOUNTER

Now think about a doctor's visit that happens in the future where a decision is made in exactly the way you want. Tell me how you want your doctor to be involved. (*show illustration*)

- ☐ I prefer to make the decisions about which tests or treatments I receive
- ☐ I prefer to make the final decision about which tests or treatment I receive after seriously considering my doctor's opinion.
- ☐ I prefer that my doctor and I share responsibility for deciding which tests or treatments I receive.
- ☐ I prefer that my doctor make the final decision about which tests or treatments I receive after seriously considering my opinion.
- ☐ I prefer to leave all decisions about which tests or treatments I receive to my doctor.

Cognitive Interviewing Probes:

- Was the way you want decisions to be made offered as a choice in the previous question?
- Can you tell me in your own words how you want decisions made?
- Can you explain why you chose the option you did?
- In a perfect scenario, what kinds of things would you want your doctor to consider when forming opinions about the treatment you would receive?
    - Spirituality? Religion? Cost?
- Additional probing questions when necessary.

Now think about a doctor's visit that happens in the future where a decision is made in exactly the way you want. Tell me how you want [COMPANION] to be involved. (*show illustration*)

- ☐ I prefer to make the decisions about which tests or treatments I receive
- ☐ I prefer to make the final decision about which tests or treatment I receive after seriously considering [COMPANION]'s opinion.
- ☐ I prefer that [COMPANION] and I share responsibility for deciding which tests or treatments I receive. I prefer that [COMPANION] make the final decision about which tests or treatments I receive after seriously considering my opinion.
- ☐ I prefer to leave all decisions about which tests or treatments I receive to [COMPANION].

Cognitive Interviewing Probes:

- Was the way decisions were made offered as a choice in this question?
- Can you tell me about the decision in your own words?
- Can you explain why you chose the option you did?
- What kinds of things would you want [COMPANION] to consider when forming their opinions about the treatment you would receive?
    - Spirituality? Religion? Cost?
- Additional probing questions when necessary.

NOLAN ET AL. (2005) QUESTIONS

In making decisions about your treatment right now, how do you weigh the input of your doctor and the input of [COMPANION]?
Clarify if necessary.

- ☐ My doctor's input weighs most heavily.
- ☐ [COMPANION]'s input weighs most heavily.
- ☐ My doctor's input and [COMPANION]'s input are about equally important.

Now think about a decision about your treatment being made at a time when you were unconscious and seriously ill. How would you weigh the input of your doctor and the input of [COMPANION]?
Clarify if necessary.

- ☐ My doctor's input weighs most heavily.
- ☐ [COMPANION]'s input weighs most heavily.
- ☐ My doctor's input and [COMPANION]'s input are about equally important.

INFORMATION PREFERENCES

When people face a serious illness, they have different preferences about what they are told. They also may want different things considered in making decisions. I am going to ask you about what you want the doctor to tell you if you are diagnosed with a serious illness.

	Agree	Neutral	Disagree
All the information the doctor can give me			
How the condition will affect my goals			
How the condition will affect my relationships			
Pain			
Difficulty breathing			
Inability to recognize friends or family			
Trouble getting out of bed and moving around on my own			
Feeling confused			
Trouble eating on my own			
Nausea or vomiting			
Trouble getting dressed on my own			
Trouble bathing on my own			
How long I am likely to live			
Ability to live where I live now			
Ability to make decisions about my own care			

CONCLUSION

I have asked you many questions about your preferences for making medical treatment decisions. Is there anything else you would like to tell me about how you want decisions about your care to be made?